



# VOICE OF THE DIABETIC

## A SUPPORT AND INFORMATION NETWORK

The Diabetics Division of The National Federation of the Blind

Volume 5, No. 4

Fall Edition

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### Diabetics don't give up on Braille

by Allan Nichols



Allan Nichols, a long-term diabetic, tells of his experiences with diabetes and Braille. He explains how and why diabetics should be persistent when learning Braille. Allan Nichols is a "doer" and his story is inspiring.

If you are a long-term insulin-dependent diabetic like I am, and you have attempted to learn Braille, you may have said to yourself, "Oh, I can't learn Braille, my fingers aren't sensitive enough." Unless there is a substantial loss of feeling in one's fingertips, there is hope for at least some diabetics to be able to use Braille.

I can't speak for everyone, but I can relay my own experience and give some tips that I use to read Braille, which may help those with this problem.

Long-term diabetics often have a

condition known as "diabetic neuropathy", a circulatory problem causing many of the complications that we diabetics might encounter. Neuropathy causes not only insensitivity in the fingertips and toes, it also causes blindness, kidney failure, heart attacks, and other related medical problems. I have been a diabetic for over 25 years and have suffered several of these complications.

In 1964, at the age of 13, I was diagnosed as having diabetes. It wasn't until I was 22 years old that I began noticing the first complications of diabetes.

The first complication, diabetic retinopathy, began with a hemorrhage in my left eye. Then four years later, after some photocoagulation treatments on both eyes, including laser and xenon light, I lost most of my vision.

I was first introduced to Braille in July, 1978 at The Allan H. Stuart Camp for the Blind and Visually Handicapped located on Casper Mountain near Casper, Wyoming. Camp lasted for two weeks, and I was able to learn grade one Braille, as well as other alternative techniques of blindness.

At that time, I had reasonably good tactile feeling in my fingertips and was able to pick up this skill fairly quickly even though I didn't think so at the time. My expectations of my ability to pick up Braille in such a short time were a bit naive and inflated.

At camp I used jumbo Braille, which enabled me to understand the makeup of the cells easier. Later I

was introduced to the regular-sized Braille text with which I thought I would have trouble. Now, it seems to have been just a matter of experience.

Also at that time, I didn't see the true benefits of learning Braille, other than the ability to play cards again which I had missed doing with my wife and friends. About once a week, we got together to just unwind and have fun with our card games.

After I learned to read grade one Braille, I slowly began increasing my reading speed on the cards until I was able to read nearly as fast as I had before I lost my eyesight. However, my main motivation was still little more than the ability to play cards.

After being blind for about ten

months, I began having problems with swelling in my ankles, a sign of kidney disease as I found out later. By April, 1979, I was rather sick due to kidney failure. By June I had gained 25 pounds from fluid retention due to the inability of my kidneys to

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*Voice of the Diabetic is a national publication of the Diabetics Division of the National Federation of the Blind. It is read by those interested in all aspects of blindness and diabetes. We show diabetics that they have options regardless of the ramifications they may have had. We have a positive philosophy and know that positive attitudes are contagious!*

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ISSN 1041-8490

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Columbia, MO 65201

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## Don't give up

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function properly.

Looking at it in retrospect, it is scary to think that I almost died of congestive heart failure. This condition is caused by the improper filtering of blood through the kidneys.

During this time, I did little more than exist, although I was running a small coffee shop. My regular working hours were from 7:00 a.m. to 3:00 p.m.; I worked only in the mornings on Mondays, Wednesdays, and Fridays, and dialyzed in the afternoons 1:00 p.m. to 6:00 p.m.

It was very taxing on my system, and I hated the whole regime of the restricted diet, feeling tired all the time, the severe cramping while on dialysis, not to mention the fact that my doctors treated me like a child. Also, I gained too much weight between dialysis sessions.

After almost dying a couple of times because my blood sugar and potassium levels were too high, I decided that there must be a better way to live than the way I was doing it.

After some careful investigation and evaluation, I went, in June, 1980, for a kidney transplant. I told myself and several other people that it would be better to die on the operating table in the pursuit of a good kidney than to continue the agonizing way I was living. It turned out to be one of the wisest decisions that I have ever made. If I had it to do over again, even with the problems that I encountered then and since, I would go through it all again. Despite some complications after the transplant, I now had a good working kidney. And, for the first time in a long while, I felt human again.

Even anti-rejection medication for the transplant was not without its own complications. Shortly after my operation, I noticed that I was losing the feeling in my toes. Despite this concern, I was able to put my life back together. However, about five weeks after leaving Bishop Clarkson Memorial Hospital in Omaha, Nebraska, I had to return for three weeks when one of my old kidneys became infected; it had to be removed.

At this point, I had several things going against me which might have reduced my circulation. First, my diabetes continued to be a factor. Second, I had just spent a year on renal dialysis with all of its complications, not to mention all of the surgeries involving anesthesia and pain killers. Finally, there was a new problem of which I was ignorant for several years. That was the problem of the anti-rejection medications, prednisolone and Immuran. Prednisolone, which is similar to prednisone, a steroid, was given to me. I was the first patient to use it to prevent kidney rejection. It offered the benefit of not allowing calcium to leak from my bones.

There is, however, a complication

with these drugs. Recently I listened to some articles about transplantation in the *Voice of the Diabetic*, and I discovered that we transplant patients have a greater risk of amputation.

Sure enough, I was one of the unfortunate ones to be faced with not one but two amputations of my feet, which developed after two separate incidents of infected sores on them.

The first one took place in 1981, when my right foot was amputated. The next one took place in 1987, beginning with a series of amputations of toes of my left foot, resulting in the loss of the lower part of my leg up to about six inches below my knee. I now have a matched set of stumps and use two artificial legs.

During this time of health problems, I had a lot of time on my hands. Since the coffee shop where I had been working closed due to its bad location, I decided that with all of this time I would teach myself to use grade two Braille.

I got some beginning textbooks from Services for the Visually Handicapped here in Cheyenne and began to work on it without an instructor. The pace was slow because of the problems associated with my neuropathy, and I was only able to work on it for short periods of time, before the Braille characters would seem to just mush together.

If I hadn't had so much unfilled time, I might have given up on the whole project. But I wanted to be able to read some magazines I had received from *National Geographic* and *Guideposts*.

I found that I had to have patience with myself so that I could learn Braille. I made several starts and stops. There were times when I would read a lot and times I would not read at all. During this time, I began to realize what advantages Braille offered, not only to read it, but to write it.

I began to use the slate and stylus which were given to me at the Casper Mountain Camp where I had first learned to use Braille.

At the time I used Braille for little more than phone numbers and short notes.

All this time on my hands also allowed me time to think, especially about how I wished I could be working at a satisfying job again. I knew that if I was ever to work again, especially in a job I would be satisfied with, I would have to learn the alternative techniques of coping with blindness. Braille would have to be high on the list of priorities, so that when I went back to college, I could take my own notes. At that point, I was introduced to the students and staff of the Colorado Center for the Blind (CCB) in Denver, at a convention of the Wyoming National Federation of the Blind.

I had been a member of the NFB since 1983, but I didn't really appreciate all of the benefits that I could gain from such an affiliation.

Talking with Dian McGeorge, director of the Colorado Center for the Blind and President of the Colorado affiliate of the National Federation of the Blind, and others convinced me that I could gain the necessary skills that I needed to compete on equal terms with my sighted counterparts at college and in the job market.

It took a lot of haggling with the Wyoming rehabilitation agency counselors but, in February of 1989, I began attending the Colorado Center for the Blind in Denver.

The changes made in the lives of those fortunate enough to attend such a facility are dramatic! Besides the training in cane travel, daily living, Braille, and using the computer for the first time, we engaged in special activities such as cross-country skiing and a six-week course in technical rock climbing.

I began feeling good about myself as a blind person. Using Braille began to make some sense when it came to using it in everyday life.

I began using it to make grocery lists; to balance a checkbook and to take messages at the apartments and at the center. Using Braille more increased my reading speed.

I was really enjoying my training at the CCB, especially attending the convention of the National Federation of the Blind, held in July, 1989 in Denver.

My whole world came crashing down at the close of the convention. This was partly due to the walking I did during the convention and partly due to the heat during this time. (It was over 100 degrees for most of the week.) At this time I developed a sore on my right leg where my stump was rubbing on the inside of my artificial leg. The sore became infected, and soon I was unable to put on my right prosthetic leg. I ended up having to spend more time in the hospital and had several setbacks before I could resume my training at the CCB.

Again, I had more time on my hands. I had to use a wheelchair or a walker to get around. This time I was determined to make the best use of my time by earnestly working on my Braille.

To become more proficient in Braille, I began to use the Perkins Braille. To keep up both my Braille skills and my spirits, I began writing some original jokes for my family and the students and staff at the Colorado Center.

I found that using the Perkins Braille was a lot faster than using the slate and stylus, although they both have their uses at different times.

I also got some Braille material to read, although there is precious little found in Cheyenne, Wyoming. I read my first two books just for pleasure, *All Quiet on the Western Front* and *The Bridge at Toko Ri*.

I made some discoveries about how I could increase my reading speed and comprehension. These included making sure that my diabetes was under control, getting regular ex-

ercise, (especially before trying to read), having the Braille material at the right level to facilitate circulation, and having my fingers warm enough.

The most important of these was keeping my blood sugar properly regulated, for my most effective reading was done when a desirable blood sugar was reached. I found that keeping my arms at a slightly downward slant while reading improved blood circulation to my hands. I also found that reading in a warm room or warming up my hands after being outside during cold weather helped me with character recognition.

My leg finally healed, enabling me to continue my training at the CCB, so in mid-October I returned to the Center to finish my training there.

I believe that the whole experience gave me more of an appreciation for the abilities I possess instead of worrying about any diminished capacity that I might have.

I graduated from the Colorado Center for the Blind on December 8, 1989, with my next step to be the continuation of my college training.

Presently, I am attending Laramie County Community College in Cheyenne. I plan to complete my Bachelor's Degree at the University of Wyoming in Laramie and eventually work toward becoming a marriage and family counselor.

It has been my experience while taking my psychology and computer courses that Braille is an indispensable tool for me, even though I do use the talking computer for some applications.

When it comes to taking my own notes, Braille is quite valuable in the learning process. I have discovered that just the procedure of typing Braille notes from the textbook has enabled me to comprehend the material more easily than I would be able to if I were merely listening.

Both my Braille and computer keyboarding skills have improved while I have been back in college. I have not been tested on my typing speed lately, but the true test has been using both skills effectively and expediently. I have found that I can increase my reading speed and remember all of the abbreviations which used to give me trouble.

My typing from just my computer textbook has become quite a voluminous pile of notes.

Another benefit of using the Perkins Braille has been an increase in my reading speed as my typing speed increases. I believe that the two are interrelated.

I don't know how fast I can become in my reading and writing of Braille, but I know that I wouldn't want to return to the way I was before I learned how to use this valuable tool. I would urge any blind person to use Braille if at all possible. Especially if you are a diabetic and have some feeling in your fingers, be sure you use it or you will lose it.





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## Neuropathy yes — Braille yes

by Nancy Scott



Nancy Scott says that diabetics who have trouble reading Braille because of nerve damage, shouldn't give up. Nancy is a long time member of the National Federation of the Blind, and knows the importance of Braille.

I attended a Diabetics Division seminar at last year's Pennsylvania NFB convention. I have both friends and relatives who are diabetics, so the subject is of particular interest to me. One of the pieces of advice that Karen Mayry gave me was so helpful to a friend of mine, that I thought I'd share the story. (Editor's note: Karen Mayry is President of the Diabetics Division of the NFB.)

Pauline is a brittle, juvenile diabetic who lost most of her vision about five years ago. She was wise enough to take some important steps in her quest for independence, such as getting a guidedog and learning some basic Braille from a friend. She used a course from the Hadley School (which offers free correspondence courses to blind people in a wide range of subjects) as a back-up. With practice, she was able to write phone numbers, shopping lists, and labels fairly easily.

As time went on, problems with neuropathy and the multiple finger sticks for blood testing made it more difficult for her to read the Braille which she could, by that time, easily write.

I asked Karen Mayry if anything could be done and she suggested Jumbo Braille. Jumbo Braille is the

same as regular Braille except that the dots are farther apart, making the Braille cell larger. Another friend of mine had a Jumbo machine; we tried it, and it worked very well.

In this case, the story had an even happier ending because my friend with the Jumbo Braille Writer wanted to return to regular Braille. (He is not diabetic). We simply switched their two brailers, and everybody was happy. Pauline is now working on Grade Two Braille, and I am searching for a Jumbo slate for her. Pauline is a better slate-user than I am, and I've used Braille all my life. I guess she'll be teaching me some things now.

**From the Editor:** Since diabetes is the leading cause of new blindness in the adult population, there are thousands of diabetics who become blind each year due to diabetic retinopathy. Blindness does not have to be the great tragedy that it is often considered to be.

With training and opportunity, blind persons can learn alternative techniques so that they can remain independent, active, and involved in the mainstream of society.

Braille is easy to learn, and a great asset for blind persons. Due to neuropathy or nerve damage, some diabetics lose feeling in their fingertips, and must use Jumbo Braille, which is explained in the above article. Some blind diabetics have severe neuropathy and cannot feel the Jumbo Braille dots very easily, if at all.

For those unable to use Braille, there is a large tactile identification system available. It doesn't replace Braille, but it is a good alternative. Training materials cost about \$25.00 and equipment about \$40.00. The approximate total cost, about \$65.00, includes cassette instructions. The cost is less for persons not requiring the entire unit. Contact: Fishburne Enterprises, Inc., 221 N. Gordon Dr., Winston-Salem, NC 27104; telephone: (919) 765-2928.

If you are legally blind and can't read normal-size print without holding the book very close to your eyes, then you should learn Braille. Please feel free to contact the National Federation of the Blind, 1800 Johnson St., Baltimore, MD 21230; phone: (301) 659-9314.

erly diagnosed and treated, type 1 diabetics can lead to coma and death.

Now, medical science has developed its own early warning system for those with family histories of type 1.

For families in which one child is a known type 1 diabetic, the test is 90 percent accurate in telling which other siblings are at risk, says

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*If you or a friend would like to remember the Diabetics Division of the National Federation of the Blind in your will, you can do so by employing the following language:*

*"I give, devise, and bequeath unto Diabetics Division of the National Federation of the Blind, 1800 Johnson Street, Baltimore, Maryland 21230, a District of Columbia nonprofit corporation, the sum of \$\_\_\_\_\_ (or \_\_\_\_\_ percent of my net estate" or "the following stocks and bonds: \_\_\_\_\_") to be used for its worthy purposes on behalf of blind persons."*

## Acceptance is key to a full life

by Robert M. Shornick

You've been told you have diabetes. "Why me? What have I done to deserve this?" you mutter to yourself. The news is frightening. The doctor called it a "chronic" disease. Your handy dictionary shows you the word "chronic" has synonyms like continuous, constant, perpetual. It slowly sinks in; this is not a temporary thing. It's not going away. There will be no return to "just as I was before."

That's right, you won't be what you were before. What you will be depends on the attitude you shape toward this turn in your life. The healthful attitude is total acceptance of your disease. Here's why: Acceptance is the platform on which you build proper management techniques that lead to a full and productive life.

Acceptance is based on the understanding that many of the changes life imposes upon us are beyond our control. The mating decisions made by your ancestors were beyond your control. You didn't choose your parents, and they didn't choose theirs, etc.; however, we all are products of the genes of our ancestors. Through the generations, those genes have passed along traits and characteristics—some good, some not so good. Diabetes is in large part hereditary.

So, your family tree had some branches where diabetes prevailed. Something in your life happened to bring diabetes to full bloom in you. That's logical, and you understand it.

From that point of understanding, you move to the realization that you have choices in how you face up to this disease. The right choice must be the one most likely to enable you to cope with, to live with, this unwanted intruder. Facing up realistically, facing up maturely, involves "accepting what I am so I can take charge of my destiny."

If you have problems with acceptance, try this. Look in a mirror and say these words aloud: "I have diabetes. At present there is no cure in sight, but it can be managed. When I manage my diabetes, I can lead a full and productive life. Therefore, I will manage my diabetes and lead a full and productive life."

You may run into two distinct reac-

tions from your friends and acquaintances—both extreme ones.

One reaction is along the lines of "Diabetes, big deal, diabetes is like a headache. Take a pill, get plenty of rest. It's really nothing." That is wrong: diabetes is considerably more than that.

The other reaction is quite the opposite: "Diabetes—oh, you poor thing. You shan't be here long, or you'll lose a leg, or go blind." This reaction is based on inaccurate knowledge about the disease. The diabetic is vulnerable to complications, but such eventualities are far from certain.

So if you are newly diagnosed, don't be thrown off balance by what people may say to you. Most people know very little about what diabetes is and isn't. Don't let well-intentioned, uninformed people cause you undue concern.

You can go from a newly diagnosed state to an adjusting state to a self-managed state. It starts with acceptance.

(Note: This article appeared in the summer 1988 issue of *Exchange*, by the ADA of Missouri. It is old, but the information provided is not.)

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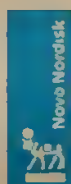
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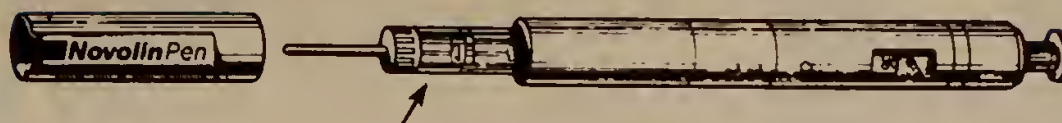


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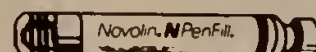


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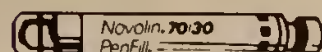
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## Imagine there's no diabetes

by Noreen Harmer



Noreen Harmer, a long-term diabetic, "dreamed that she would wake up one day and not have diabetes anymore." In 1983 she had a pancreas transplant and hasn't taken an insulin injection for more than seven years.

"Every day, for the rest of your life, you will have to take a shot of insulin," said Dr. Paul. There were tears in his eyes.

"Oh no, not me!" I immediately stated. Dr. Paul stood quietly for a moment while my life changed forever.

"You can do that or you can die," he said softly.

There was a split-second hesitation. "I bet I can do it," I said in a voice that convinced us both.

It was 1960. I was ten years old. I was never really young again. It was the beginning of a lot of responsibility and the limitation of choices. Diabetes—a life of rules, where every mouthful of food, every game of jump rope, every infection, every response of anger or joy or sadness, every hour of every day must be calculated and measured against each other. These factors control blood sugar, which controls life.

Over the years I performed the tasks of measuring food, eating on a strict schedule, testing my urine for sugar and giving myself injections—almost always with a positive attitude. People often commented on how easily I had accepted my condition. But I had a secret: I believed that someday—somehow, this would all be over. I dreamed I would wake up one day and not have diabetes anymore.

It wasn't quite that easy, but in 1983, after twenty-three years of living with diabetes, I woke up after transplant surgery and a nurse said, "Noreen, it's working, the pancreas is working, you don't have diabetes anymore." And I had my moment.

Most of my life I lived with the physical and psychological limitations of chronic disease, but I was always searching. Searching for reasons, for better methods of treatment, for people in the medical field who believed there was another way. Searching for a cure.

Pancreas transplantation is a cure for diabetes. Newspapers, television, and magazine articles have stated many times, there is "no cure for diabetes." I have not taken an injection of insulin for nearly seven years. My blood sugar remains normal, I eat when I want and whatever I want. This may not last, I could reject this organ tomorrow, but at this moment—I am cured.

Life is incredible, not fair or easy but incredible. I am alive, I am cured of an incurable disease, I have a healthy teenage son, and I work in the same hospital where I was first told about my diabetes. But now, I am the Diabetes Educator instead of the patient.

In 1985 I went to the hospital administrators with a plan to start a diabetes education program. I was not an R.N. and had not yet completed my degree in Health Education, but when I told them I wanted to teach people with diabetes how to take care of themselves until they too could be cured, they believed in my

dream. With support from the staff and community I developed a program to educate and support people with diabetes and their families. Hundreds of patients have helped me learn how to teach. It has been a tremendous challenge and rewarding beyond all expectations.

The most difficult part of life after transplantation is the problems that can occur from the immune system being kept suppressed. I have developed two viruses which continue to linger due to the drugs I take to maintain this pancreas. While it's sometimes a struggle to live with the many unknowns, the other option, the continuation of complications, was not what I would choose for my life. I was given an opportunity that few have ever had. I continue to savor each moment, to search for new and better ways to help people learn about diabetes while the search for the cure continues.

John Lennon sang "Imagine there's no heaven." To change his lyrics a little:

*Imagine there's no diabetes,  
It's easy if you try.  
No injections, no blindness,  
Eating apple pie.*

*"You may think I'm a dreamer  
but I'm not the only one."*



## The Federation at fifty

*An address delivered by Kenneth Jernigan at the Banquet of the Annual Convention of the National Federation of the Blind, Dallas, Texas, July 5, 1990.*



Kenneth Jernigan, Executive Director, National Federation of the Blind, gives the banquet address at the 50th annual convention of the Federation.

If the engineers of 1800 had possessed complete drawings for a transistor radio (one that could be bought today for \$10), they couldn't have built it, not even if they had had billions or trillions of dollars. They lacked the infrastructure—the tools, the tools to build the tools, and the tools to build those; the plastics, the machines to make the plastics, and the machines to make the machines; the skilled work force, the teachers to train the work force, and the teachers to train the teachers; the transportation network to assemble the materials, the vehicles to use the network, and the sources of supply. All of this is generally recognized, but it is far less well understood that what is true of material objects is also true of ideas and attitudes. In the absence of a supporting social infrastructure of knowledge and beliefs, a new idea simply cannot exist.

So far as I can tell, there are only three possible reasons for studying history—to get inspiration, to gain perspective, or to acquire a basis for predicting the future.

In 1965 Dr. Jacobus tenBroek, the founder and leader of our movement, spoke at our twenty-fifth banquet, reviewing the first quarter century and charting the road ahead. We were meeting in Washington, and more than a hundred members of Congress were present. I was master of ceremonies, and some of the rest of you were also there. Tonight (twenty-five years later) we celebrate our Golden Anniversary, and the time has once again come to take stock. Where are we, where have we been, and where are we going?

In a sense the history of our movement begins in the distant past—in the medieval guilds and brotherhoods of the blind in Europe, in the tentative stirrings of organization in China, and even earlier—but the National Federation of the Blind is es-

entially an American product. Its genesis is native. Although (as we all know) Dr. Jacobus tenBroek presided at the founding of the National Federation of the Blind in 1940 at Wilkes-Barre, Pennsylvania, he had a teacher (Dr. Newel Perry), who laid the foundations and served as precursor. And Dr. Perry, in turn, had a teacher, Warring Wilkinson.

Most of what we know about Wilkinson is contained in the eulogy which Dr. tenBroek delivered at the time of Dr. Perry's death in 1961, but our knowledge is sufficient to tell us that Wilkinson was a worthy teacher of the teacher of our founder. He was the first principal of the California School for the Deaf and Blind. He served in that capacity for forty-four years, from 1865 to 1909. He not only loved his students but also did what he could to move them toward the main channels of social and economic participation. Particularly, he saw the potential in young Perry, sending him from the California School for the Blind to Berkeley High to complete his secondary education. To do this Wilkinson (who was ahead of his time both in his understanding of education and the needs of the blind) had to overcome numerous obstacles.

I was fortunate enough to know Dr. Perry, meeting him when I moved to California in 1953. He was then eighty, and he spent many hours with me reminiscing about what conditions for the blind were like when he was a boy. He came to the California School for the Blind when he was ten—"penniless, blind, his father dead, his home dissolved. Two years earlier he had lost his sight and nearly his life as the result of a case of poison oak, which caused his eyeballs to swell until they burst and which held him in a coma for a month." It was at the School, of course, that he first met Warring Wilkinson.

While going to high school (from which he graduated in 1892) he lived at the California School for the Blind. He also lived there while attending the University of California from 1892 to 1896. His admission to the University (as had been the case with high school) had to be secured over strong resistance. Again, Wilkinson was the pathfinder, young Perry his willing and anxious instrument. "Wilkinson's role in Perry's life as a youth can hardly be overestimated: father, teacher, guide, supporter—in Perry's own words, 'dear Governor.'"

After graduating from the University, Dr. Perry devoted himself to further education and to the search for an academic job. "He took graduate work at the University of California, meanwhile serving successively as an unpaid teaching fellow, a paid assistant, and finally as an instructor in the department of mathematics. In

1900, following a general custom of that day, he went to Europe to continue his studies. He did this for a time at the University of Zurich in Switzerland and then at the University of Munich in Germany. From the latter he secured in 1901 the degree of Doctor of Philosophy in Mathematics, with highest honors.

"He returned to the United States in 1902, landing in New York, where he was to remain until 1912. He had about eighty dollars in capital, a first-class and highly specialized education, and all of the physical, mental, and personal prerequisites for a productive career—except one, eyesight.

"During this period he supported himself precariously as a private coach of university mathematics students. He also applied himself to the search for a university position. He displayed the most relentless energy. He employed every imaginable technique. He wrote letters in profusion. In 1905 he wrote to 500 institutions of every size and character. He distributed his dissertation and his published article on mathematics. He haunted meetings of mathematicians. He visited his friends in the profession. He enlisted the aid of his teachers. He called on everybody and anybody having the remotest connection with his goal.

"Everywhere the outcome was the same. Only the form varied. Some expressed astonishment at what he had accomplished. Some expressed interest. One of these seemed genuine—he had a blind brother-in-law, he said, who was a whiz at math. Some showed indifference, now and then masked behind polite phrases. Some said there were no vacancies. Some said his application would be filed for future reference. One said ironically: 'For what—as an encouragement to men who labor under disadvantages and who may learn from it how much may be accomplished through resolution and industry?' Some averred that he probably could succeed in teaching at somebody else's college. Many said outright that they believed a blind person could not teach mathematics.

"Many of these rejections may, of course, have been perfectly proper. Many were not. Their authors candidly gave the reason as blindness."

Dr. Perry failed not because of lack of energy or qualification but because the necessary infrastructure of attitudes and beliefs did not exist to allow it to be otherwise—so he did not find a job in a university. Perhaps it was better for the blind (for those of us gathered here tonight) that he did not—but for him what pain! What absolute desolation and misery! And he had to face it alone—no family, no supporting organization of the blind—only himself and the bleak wall of continuing rejection year after

year. He might have quit in despair. He might have become embittered. But he did not. Instead, he returned to California and settled down to build for the future. If he could not have first-class treatment for himself, he was absolutely determined that at least the next generation of the blind would not be denied.

He taught at the California School for the Blind from 1912 to 1947—and day after day, month after month, season after season he exhorted and indoctrinated, preached and prepared. He was building the necessary infrastructure of ideas and beliefs. Those who were his students went on to become his colleagues, and as the number grew, the faith was kept. There would be a statewide organization of the blind in California. It did not happen until 1934, but when it came, it was built on a solid foundation. And there would also be a National Federation of the Blind—but not yet.

Dr. Perry was to that generation what Warring Wilkinson had been to him. In the words of Jacobus tenBroek, his most brilliant student and the man who would lead the blind in the founding of their national movement: "We were his students, his family, his intimates, his comrades on a thousand battlefronts of a social movement. We slept in his house, ate at his table, learned geometry at his desk, walked the streets interminably by his side, moved forward on the strength of his optimism and confidence."

Dr. tenBroek graduated from Berkeley High School in 1930 with, as he said, "plenty of ambition but no money." He was prepared to enter the University of California but was denied state aid to the blind, a program then newly instituted as a result of Dr. Perry's efforts in sponsoring a constitutional amendment, which had been adopted by the voters of California in 1928. In Dr. tenBroek's words, "The reason for the denial was not that my need was not great. It was that I intended to pursue a higher education while I was being supported by the state. That was too much for the administrative officials. Almost without discussion, Dr. Perry immediately filled the gap. Just as Warring Wilkinson had earlier done for him," said Dr. tenBroek, "he supplied me with tuition and living expenses out of his own pocket for a semester while we all fought to reverse the decision of the state aid officials.

"It was," Dr. tenBroek said, "ever thus with Dr. Perry. The key to his great influence with blind students was, first of all, the fact that he was blind and therefore understood their problems; and second, that he believed in them and made his faith manifest. He provided the only sure foundation of true rapport: knowl-

(Continued on page 8)



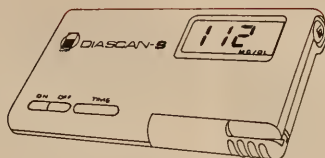
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## The Federation

(Continued from page 6)

edge on our part that he was genuinely interested in our welfare."

So the new generation came to maturity, and Jacobus tenBroek was to be its leader. Born in 1911 on the prairies of Alberta, Canada, he was blinded by an arrow in a childhood game and moved to California to enter the school for the blind. He went on to earn five academic degrees—from the University of California at Berkeley a bachelor's in 1934, a master's in 1935, a law degree in 1938, and a Doctorate in Jurisprudence in 1940; and from the Harvard Law School a Doctorate in Jurisprudence in 1947. There is no need for me to talk to this audience about Dr. tenBroek's brilliance—his learned articles and books, his chairmanship of the California Board of Social Welfare, his scholarly pre-eminence and national acclaim, his writings on constitutional law that are still the authoritative works in the field. Rather, I would speak of the man—the warm human being who fought for acceptance, led our movement, and served as my mentor and role model—the man who was my closest friend and spiritual father.

When Dr. tenBroek was first trying to get a teaching position in the 1930s, the climate of public opinion was better than it had been a generation earlier, but he faced many of the same problems which had confronted Dr. Perry—and sometimes with identical letters from the same institutions. "It was," he said, "almost as if a secretary had been set to copying Dr. Perry's file, only changing the signatures and the name of the addressee."

Here is what Dr. tenBroek wrote to Dr. Perry in March of 1940. At the time he was studying at Harvard:

"Last November a large midwestern university was looking for a man to teach public law. Having read my published articles but knowing nothing else about me, the head of the department in question wrote a letter to the University of California inquiring whether I would be available for the position. Cal. replied that I would and accompanied the answer with a considerable collection of supporting material. However, when the department head learned that I was blind, the deal was off although none of the competing applicants had as good a paper showing.

"This incident seems to me of particular interest because, although I have been refused other jobs, this was the first instance in which blindness could be traced as the sole explanation for rejection. Of course, in other cases blindness was also the determining factor, but the fact could not be demonstrated as well."

There were other letters and other rejections—but on June 8, 1940, Dr. tenBroek was able to write to Dr. Perry:

"We have justification for hanging

out the flags and ringing the bells. I have been offered and have accepted a job at Chicago University Law School. The job pays \$1,800, is denominated a half-time position, and lasts for only a year. But it is a job nevertheless. And the Harvard people, who exerted no end of pressure to get it for me, regard it as an excellent opportunity. The position is designated 'tutorial fellowship' and consists in supervising the research of the first- and second-year law students. It involves no actual classroom teaching, except possibly by way of an occasional fill-in job."

This was how Dr. tenBroek (the man who fifteen years later was to win the Woodrow Wilson Award for the outstanding book of the year in political science and who was always the most sought-after professor at the University of California) was to begin his teaching career. Yet, even today there are sighted people (and also some of the blind—people who ought to know better) who tell me that the blind are not victims of discrimination. Yes, the tenBroek job search was fifty years ago, but you know and I know that we have not yet come to first-class status and equal treatment in society. The framework of ideas and beliefs to make it possible, though long in the building, is still not complete. Warring Wilkinson, Newell Perry and his students, Jacobus tenBroek and the founders of our movement, and the Federationists of succeeding decades have worked year after year to improve the climate of public acceptance and make opportunity available for the blind, but the job is not yet finished. Each generation has built on the work of the one before it. Each has fought and hoped, dreamed and struggled for the one to follow—and also for the blind then alive.

What we have done must be seen in perspective: for no act of the past (no gain or denial) is irrelevant, and no present behavior of ours can be divorced from tomorrow. We are close to freedom, and we must finish the journey.

1940 was notable for something else besides Dr. tenBroek's debut at the University of Chicago. It was also the year of the founding of this organization. With the passage of the Social Security Act in 1935 the federal government had supplanted the states in providing assistance to the blind. In 1939 Congress and the Social Security Board combined to pressure the states having the most forward looking programs (chief among them California but also Pennsylvania, Missouri, and Wisconsin) to repeal their progressive laws. This supplied the immediate impetus for the formation of the Federation, but of course the momentum had been building for a generation. The event occurred at Wilkes-Barre on November 15 and 16, 1940, coincident with the convention of the Pennsylvania Federation of the Blind.

In a letter to Dr. Perry dated November 19, 1940, Dr. tenBroek said

in part: "The confab at Wilkes-Barre gave birth to an organization, the National Federation of the Blind—of which you, vicariously through me, are president. The long-range aims of the organization are the promotion of the economic and social welfare of the blind, and its immediate and specific aims are the sponsorship of the principle of Senate Bill 1766 and an amendment of the Social Security Act."

"Seven states were represented at the organizational meeting—Minnesota, Wisconsin, Illinois, Missouri, Ohio, Pennsylvania, and California. We arrived in Wilkes-Barre in the middle of Friday afternoon..."

"On Saturday morning, while the Pennsylvania state meeting was going on, I had several back-of-the-scenes conversations with Pennsylvania leaders... In the afternoon... we drew up a skeleton constitution, which we presented to a meeting of all of the delegates to the national meeting, beginning about four o'clock and ending about the same time twelve hours later... The meeting was interrupted at 5:30 in the afternoon long enough to give the other delegates a chance to eat dinner, and the Pennsylvania leader (Gayle Burlingame) and me a chance to appear on the local radio, where we lambasted hell out of the Social Security Board."

On January 4, 1941, Dr. tenBroek wrote to Dr. Perry concerning the details of getting the new organization started. "With the National Federation of the Blind not yet two months old," he said, "its permanence is definitely assured. The factor guaranteeing that permanence is the closely knit nucleus composed of Minnesota, Pennsylvania, and California. We three have now had enough experience with each other to know that we can make a go of it... We can add to this trilogy the state of Wisconsin."

"I had a letter from Minnesota yesterday to the effect that they are ready to pay their assessment but that they wish assurance that Pennsylvania and California are also ready before they mail their check. I also had a letter from Pennsylvania stating that it is ready but wishes assurance that Minnesota and California are ready. I have written to both of these states requesting them to make out their checks, payable to the Treasurer of the National Federation, and to send them to me, with the stipulation that I shall not forward them to the Treasurer until I have the dues from each of the states of California, Pennsylvania, and Minnesota. Consequently, if California is ready, I suggest that you follow the same procedure..."

But the new president did not limit himself to procedural matters. The Federation immediately assumed its present-day role of working to improve the quality of life for the nation's blind. In a letter to Dr. Perry dated March 15, 1941, President tenBroek described the efforts he had been making to get changes in the

administration of public assistance to the blind. Here, in part, is what he said:

"After a week in Washington I have more unsocial exchange to report than specific accomplishment... Gradually working our way upward, Gayle Burlingame and I first presented our case to Jane Hoey, director of the Bureau of Public Assistance, and her associate, a lawyer named Casius. Next we went to Oscar Powell, executive director of the Social Security Board; and finally to Paul V. McNutt, administrator of the Federal Security Agency. Hoey is simply another social worker of the familiar type but with a higher salary than most. Casius has lost none of his qualities since Shakespeare described him, except that his wit has been sharpened by a little legal training. Powell is a very high calibre man with a fine sense of argumentative values, a considerable store of good nature, and unusual perception. He simply is not a believer in our fundamental assumptions. McNutt, on the other hand, is a lesser Hitler by disposition and makes our California social workers look like angels by comparison."

"Hoey and Powell had argued that the new ruling of the Board did not necessarily result in a reduction of a recipient's grant by the amount of his earnings or other income. McNutt took the position that it did and, moreover, that it should. 'Are you saying to us,' I asked McNutt, 'that blind people should have their grants reduced no matter how small their private income and no matter how great their actual need?' His answer was that he was saying precisely that. I formulated the question in several other ways, only to get the same reply. I can't say that I wasn't glad to get this official declaration from McNutt since it provides us with an official declaration by the highest administrator of them all that ought to be of immense propagandistic value to us. Moreover, McNutt's conduct during the conference has provided us with the most perfect example of the arbitrary and tyrannical methods of the Board that we could hope to have."

"In the remaining week that I shall stay in Washington, we shall attempt to carry our appeal to the last administrative step. Senator Downey of California and Senator Hughes of Delaware are attempting to secure for us appointments with Mrs. and President Roosevelt."

"As things stand, the only course open to the blind of California is to urge the legislature to retain the blind aid act in its present form and tell the federal government to go to hell. Even if we can get a favorable amendment to the Social Security Act, it certainly will not be until after the California legislature adjourns."

This is what Dr. tenBroek wrote in 1941, and although we have often said in this organization that the first task which the Federation faced after its founding was to help the blind of the nation get enough money for



bare survival, I sometimes wonder if we have made the point with sufficient clarity to convey the desperation of it. The report which was prepared following the 1941 convention of the Federation in Milwaukee says in part:

"Mr. Stephen Stanislevic of New York City reported as follows: 'The blind population of New York State is roughly estimated at 13,000. Of these, more than half are in New York City. A very small number of our people, a few hundred in all, are at present employed in sheltered industries, on government projects, at newsstands, or in miscellaneous enterprises. The majority depend for sustenance either upon private bounty or upon Social Security grants. The average monthly grant per individual is \$27 in New York City and \$23 in the up-state counties. This is the paltry pittance which the wealthiest state in our Union sees fit to dole out to those of its citizens who are blind.'

"Mr. Hugh McGuire explained that in Indiana there are approximately 2,600 blind and that between 2,200 and 2,300 are drawing assistance with the monthly average of \$20."

That was forty-nine years ago, and much has happened in the interim. Not that it happened by chance, of course. Mostly we made it happen. How many times since 1940 has the National Federation of the Blind led the way in social reform in this country, not only for the blind but also for others? To mention only three examples, we pioneered exempt earnings for the recipients of public assistance; we pioneered fair hearing procedures in rehabilitation and other public programs; and we pioneered jobs for the disabled in government service.

As I have already said, our first task as an organization was to initiate programs to enable the blind to get enough to eat. In 1940 and the decades immediately following, most of the blind of this country were desperately poor, and there were almost no government programs to help. When people are hungry, little else matters. Later (although many of us were still in poverty—and, for that matter, are now) we worked on rehabilitation and employment, and today we emphasize civil rights and equal participation in society. But essentially our role is what it has always been—seeing that blind people get equal treatment and a fair shake.

It is not only in basics but also in detail that our operation today is often much the same as it was in past decades. Let me give you a rather specialized example. I have made a lot of banquet speeches at these conventions, and certain key ideas are central to them all. I can sum up the essentials in a few sentences. The real problem of blindness is not the blindness itself but what the members of the general public think about it. Since the agencies doing work with the blind are part of that general public, they are likely to possess the same misconceptions that are held by the broader society. The blind, too, are part of that broader so-

ciety, and if we are not careful, we will accept the public view of our limitations and thus do much to make those limitations a reality. The blind are not psychologically or mentally different from the sighted. We are neither especially blessed nor especially cursed. We need jobs, opportunity, social acceptance, and equal treatment—not pity and custody. Only those elected by the blind can speak for the blind. This is not only a prime requisite of democracy but also the only way we can ever achieve first-class status.

These are the essential points of every banquet speech I have ever made. The banquet speeches are meant to be widely circulated. They have the purpose of convincing those in work with the blind and the public at large that they should rethink their notions about blindness. They also have the purpose of stimulating our own members to increased activity and added vigor. Hopefully the speech will be sufficiently inspiring, entertaining, and literate to make people want to listen to it—and later (when it is distributed) to read it. The

difficulty is that just about the same thing needs to be said every year, but it has to be restated so that the listeners (and ultimately the readers) will feel that it is different—and maybe even new. After a while, putting it all together becomes quite a problem.

I don't think I ever talked about this matter with Dr. tenBroek, and I certainly did not attend the 1949 convention at Denver. With this background let me share some correspondence with you. Kingsley Price

(Continued on page 10)

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## The Federation

(Continued from page 9)

was a Californian, who became a college professor and was living in New York in the 1940s. In a letter dated April 8, 1949, Dr. tenBroek wrote to urge him to attend the Denver convention. "The problem does not arise," Dr. tenBroek said, "out of an unmixed desire to enjoy your company. I would like to get you to give the principal banquet address. This is something that I have not been able to dodge very often in the seven conventions that we have had. [Conventions were not held in the war years of 1943 and 1945.] The banquet address," Dr. tenBroek continued, "is a kind of focal point in which the problems of the blind, their peculiar needs with respect to public assistance, employment, and equal opportunity are formulated and presented both with an eye to rededicating and stimulating the blind persons present and an eye to enlightening and possibly converting the many sighted persons who have been invited to attend. For me, this has always been a job of rehashing and repeating certain central ideas. My imagination and new methods of statement have long since petered out. The next alternative is to get a new 'stater.' This is what I would like you to be.

"We would, of course, introduce you as a New Yorker since there are far too many Californians in the limelight as it is. We also, if we thought hard, could find one or two other chores about the convention for you to do.

"Please think this matter over as long as you want, but let me have an immediate answer."

Among other things, Dr. tenBroek obviously wanted to get Price to become more active in the movement, and he probably thought the banquet speech might be a way to do it. There has always been a tendency for the successful members of a minority to try to avoid involvement. The only trouble with this behavior is that it won't work. At an earlier period many blacks tried to straighten their hair and hide in white society, but then they realized that it was better to make it respectable to be black. The corollary, if I need to say it, (and every one of us had better know and understand it) is that it is respectable to be blind. That's what the National Federation of the Blind is all about.

No blind person in this country is untouched by our successes or, for that matter, our failures—and no blind person can avoid identification with the rest of us. This is true regardless of how the blind person feels about it and regardless of how we feel about it. Blindness is a visible characteristic, and all of us are judged by each other whether we like it or not. The feeling I have toward those blind persons who try to hide in sighted society is not anger but pity—and, yes, I am talking about those who are regarded (and who re-

gard themselves) as highly successful.

When Professor Price replied to Dr. tenBroek, he said that he might be able to come but would probably do a bad job making the banquet speech. He should not have been deceived by the light tone of Dr. tenBroek's letter of invitation, for Federation presidents take banquet speeches seriously. In a letter dated April 21, 1949, Dr. tenBroek set him straight:

Dear Kingsley:

I am not now, nor on June 20th shall I be, in the least inclined to accept a bad job in the banquet address. If I were willing to accept a bad job, I can think of at least a hundred persons of assured competence to satisfy the requirement.

The banquet address is the focal point of the whole meeting. It has come to be regarded as the most important thing that is done at a convention. Many people of influence in the community are invited to hear it. The Governor of the State often is present, and the occasion is used to give him instructions as to what his policy should be towards the blind. The address is expected to be of such a character that it can be published and circulated the nation over with some advantage to the blind.

The address must be on the subject of the nature of the problems of blindness, and the discussion should be frank and forthright. Amplification of points by way of personal experience is always helpful and attractive. One conclusion that must always be reached is that the blind should speak for themselves because they are the only qualified persons to do so.

I enclose a copy of my Baltimore address, which may give you an idea of what needs to be said. The same truths have to be retold, but the hope is that they will be dressed up in a new and fresh style, even to the point of appearing to be different truths.

One further word: It may be that the address will be broadcast direct from the banquet hall. Consequently, both speech and delivery need to be well in hand.

I hope these admonitions are solemn enough to convince you of the importance of doing a good job and yet not so solemn as to scare you away. We are desperately in need of a new voice and a new brain to do this job and a man from New York has geographical advantages as well.

Cordially yours,

In considering our past I am mindful of the fact that except for inspiration, perspective, and prediction, there is no purpose to the study of history. Certainly we can find inspiration in the lives of Warring Wilkinson, Newel Perry, and Jacobus tenBroek. Often in lonely isolation they worked for a distant future which they knew they would never see but which is our present. Using meager resources that they could ill-afford to spare, they



fought to build a framework of opportunities and benefits which constitute the underpinning and foundation of what we have today. How can we be unmoved by their story? It speaks to us across the years—calling us to conscience, giving us strength for the battles ahead, reminding us of our heritage, and underscoring our duty to those who will follow.

Yes, there is inspiration in our history, and it also gives us perspective. Otherwise we might become discouraged. Even today, with all of our work, more often than not when we come to one of these conventions and talk to the press, they assign their medical reporters to deal with us. They want to write stories about our guide dogs, the causes of blindness, and how capable we are because we can do the ordinary tasks of daily living, like cutting our food or finding our way.

But the balances are shifting. Each year a few more reporters are beginning to understand that our story is not one of physical loss, or courage in the face of deprivation, but lack of opportunity and denial of civil rights. A perfect example is the recent story in the *Wall Street Journal* about the blind who are running their own businesses. It contains not a scrap of pity, nor a wasted word about those who (though blind) are valiantly struggling to earn a living. Of course, it contains drama—but it is the drama of a people fighting to rise to first-class status in a society which treats them like children and wonders why they object.

Recently I went to the White House and talked with the President of the United States about the problems we are having with the airlines and the Federal Aviation Administration. We are being excluded from exit row seats on airplanes, but year after year the Federal Aviation Administration has said that there is no issue of safety in our sitting there. Now (because of pressure by the airlines) they have changed their minds. As we have become painfully aware, the issue of seating is only one tiny part of an overall pattern of bullying and harassment which blind persons face today in air travel. The difficulty which always confronts us when we try to discuss this issue is the talk we get about compassion and how commendable it is that we are trying to be independent—all of which is a bunch of nonsense. If we pose a hazard in exit row seats, we shouldn't sit there—and we wouldn't want to. If we don't pose a hazard in exit row seats, then we have as much right to sit

there as anybody else, and to try to make us move is an infringement of our civil rights. In either case compassion has nothing to do with it.

When I tried to convey these ideas to President Bush, his response made it clear that he had been thoroughly briefed—and by somebody who hadn't the faintest idea about the issues. In answer to my question the President said that if there was no evidence that we constituted a greater hazard than others in exit row seats, he would put an end to the rule if he had the power to do so—which, of course, he has. I wasn't very hopeful about the outcome because of two things. President Bush kept avoiding the word *blind*, gingerly referring to us as the non-sighted, and he said that Secretary of Transportation Skinner had personally tested an airplane door to see whether an individual without sight could open it—which is comparable to my going (with my lack of experience) to a hospital to see what can be done with surgical instruments.

The President assigned his lawyer, Boyden Gray, to look into the matter and get back to me. The results were what might have been expected. Mr. Gray did not talk to us, nor did he look at the video tape of our test evacuation of an airplane. Instead, he talked with Secretary of Transportation Skinner, who told him that we constituted a safety hazard—which data he ceremonially transmitted to me.

So was it just an exercise in futility? Not at all. This is where perspective helps. In 1940 Dr. tenBroek was not able even to get a hearing from President Roosevelt even though two United States senators tried to help him do it. Moreover, my talk with President Bush was only one brief skirmish in our long airline fight, and the history of our past efforts tells us that we will ultimately win. It is true that Dr. tenBroek did not get to talk with President Roosevelt, but it is also true that most of the Social Security reforms for which he fought have been adopted—and mostly they have been adopted through the efforts of the National Federation of the Blind.

Likewise, we lost the recent motion to cut off debate on our airline bill in the United States Senate, but we had fifty-six votes. And when has any other group in the blindness field ever been able to bring a bill of its own to the floor of the United States Senate and have it be the pending business of that body for several days? Never—and never with the number of votes we mustered. Again, this was only a single skirmish in an individual battle of a long war—a war which has been going on for more than a century, a war which we are winning, and a war which we intend to finish.

Yes, our history provides us with both inspiration and perspective—and it also gives us the basis for prediction. Of course, no individual can be sure of what will happen tomorrow.



row, but I feel absolutely certain that this organization will continue to grow and continue leading the way in improving the quality of life for the blind. The outward appearance of the Issues may shift, but the basics will not change—until we have achieved equal treatment and first-class status in society. And we will achieve it.

In examining our past I have not attempted to assess my own role and contributions. How could I? I have been too close, loved too deeply, put too much of my life into the process. All I can say is this: When Dr. tenBroek was dying, I made certain pledges to him. I have tried to keep those pledges. I shall always try to keep them. And when in 1986 I thought the time had come that the movement would best be served by my leaving the presidency, I did it. The decision was not easy, but I think it was right. I believe that President Maurer was the best person we could have chosen for the position and that he will lead this organization

into the twenty-first century—stronger, more vibrant, and more committed than it has ever been. And there is something more: I think the new generation that is on the horizon will provide leaders and members who will be present fifty years from now when we meet for our hundredth anniversary. We must never forget our history; we must never dishonor our heritage; we must never abandon our mission. With love for each other and faith in our hearts we must go the rest of the way to equal status and first-class membership in society. Let us march together to meet the future.

#### FOOTNOTES

1. All of the material concerning Dr. Perry except what I got from my own discussions with him is taken from "Newel Perry: Teacher of Youth and Leader of Men," by Jacobus tenBroek, *Braille Monitor*, February, 1976. The quotes from Dr. tenBroek are taken from letters in the files of the National Federation of the Blind.

## Coping: there must be 50 ways

by Margie Lawson, M.S.

What did you do the last time you felt emotionally drained, depressed, or frustrated with diabetes? Go for a walk? Talk with someone? Or go to bed and pull the covers over your head? Did it work? Did you feel better?

When diabetes is diagnosed, people react with a wide range of emotions—both positive and negative. Everyone with a chronic medical condition works through feelings of denial, guilt, frustration, anger, sadness, and loss. It may take months, even years, to cycle through these emotions. And they can resurface whenever you're reminded that your medical condition sometimes interferes with your life.

How do you successfully cope with diabetes? How can you create a

life with relatively good health and happiness?

#### How to Start

When you think about coping, what often comes to mind is that precarious state of "barely getting by." In that case, you might see coping with diabetes as putting up with it or enduring it. Actually, coping means "to contend with difficulties or to strive with success." With that definition in mind, you would cope with diabetes by facing its difficulties and working toward successful management.

What's the best, or easiest, way to do this?

There is no single answer. Various factors affect how people cope with diabetes. For instance, personalities

play important roles. So does the amount of support available from family and friends. People diagnosed at later ages seem to adjust more easily. And of course, people who require insulin face different issues than people who don't.

For some people, coping is not a problem. Others struggle for years to adjust. Counseling may help some. But you have to decide for yourself

what helps. Then you need to do more of it. The people mentioned in this article each approach their diabetes differently. Perhaps their stories will help you better understand coping and why techniques must vary.

#### Easy Come, Easy Go

Bill, 69, was diagnosed with Type II (non insulin-requiring) diabetes 15 years ago. He's always been able to follow a meal plan, exercise regularly, and take care of himself because he knows it's important. Bill copes with eating "right" by enjoying other things that are good for him and by using recipes that have been approved for diabetes. For some people it's just that easy. "My wife worried quite a bit in the beginning," he says, "but now that she sees I'm taking care of myself and feeling good, she doesn't worry too much."

On the other hand, Paul was diagnosed at 30 and didn't pay much attention to his Type II diabetes besides taking pills. Twelve years later, he began to have neuropathy and became worried about developing other complications. He finally decided he should manage his diabetes better, but he struggled unsuccessfully with it for several more years. After five months of intermittent counseling, his attitude changed from *should to want*. Now, at 48, he copes

(Continued on page 12)

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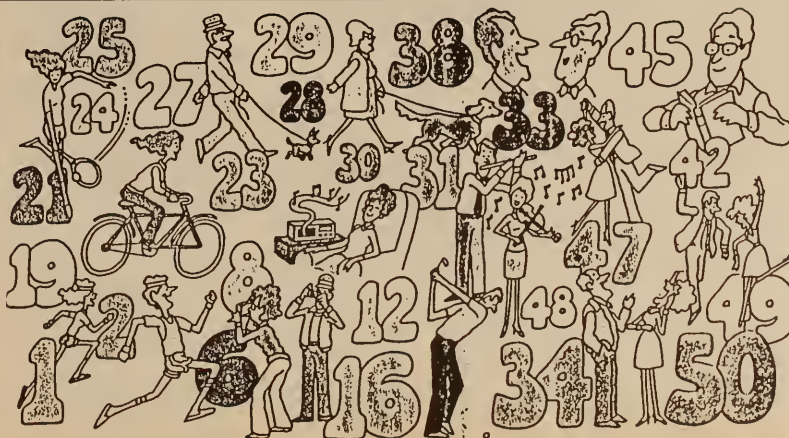


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## Coping

(Continued from page 11)

by managing his diabetes because he wants to, not because he should.

### The Fight

Some people don't just ignore diabetes, they fight it. Dee was 23 when she was diagnosed with Type I (insulin dependent) diabetes. That first year, there were periods when she just didn't follow her diabetes regimen. She didn't feel good physically or emotionally—she lived with depression, fear, guilt, anger, and frustration and rarely felt positive about herself.

A year later, Dee began to honestly address her confused feelings about diabetes. She turned her attitude around by listening to her doctor and deciding to get counseling. She now copes by accepting her diabetes. "I just do what I need to and don't make a big deal about it."

Now at age 27, Dee attributes part of her attitude change to looking at the consequences of noncompliance.

"Initially, I could pretend little flare-ups wouldn't really make a difference later in life," she said. "Then, the longer I had diabetes, I realized those frequent flare-ups meant more and more possibilities of medical complications."

However, Dee's motivation to manage her diabetes well doesn't stem from fear, but knowledge. She wants to take good care of herself.

Looking back to when she was diagnosed, Dee wishes she'd done some things differently, like reading the diabetes literature her physician gave her. (She stuck it in a drawer for a year.) She suggests learning more about diabetes by attending meetings, such as those offered by local chapters of the American Diabetes Association, and by taking classes.

"If you feel having diabetes is the end of the world," Dee says, "get some help or advice. Talking to a friend or going to counseling makes a big difference. Everybody who knows me knows I have diabetes. It's helpful to be around people who know."

"That way I don't have to explain anything when an activity is interrupted while I eat my snack. It's a hassle then, and for a brief moment I really hate having diabetes. Then I just accept the fact I have to take care of myself and get on with better things in life."

### The Cover-Up

Sometimes even people who appear to cope well may be having problems. When Ann was diagnosed at 17, she had a honeymoon period that lasted almost a year. Then she had difficulty following the diabetes regimen. She recalls frequently thinking, "Isn't there some way this can go away?" She felt diabetes was controlling her instead of her controlling it.

At 32, Ann still has difficulty dealing with diabetes, but she's learning. She sometimes seems to cope too well—at least for the benefit of her husband. Since she doesn't like to appear "down" about diabetes very often, she covers up her true feelings. This takes a lot of emotional energy and lends a sense of insincerity to relationships.

"I have to get really low and be depressed for several days before I can talk to my husband about things that are bothering me," Ann says. "In fact, he'll ask me how I'm doing and for the first day or two I'll say 'fine.'" She finally owns up to her feelings when she's at the end of her rope and has red-rimmed eyes. Then they talk about it and he helps her put things in perspective by providing emotional support.

Ann realizes the irony of the situation. She puts off what really helps until she's desperate. Maybe she'd feel better if she talked over the little things. Perhaps then she'd feel less stressed, less depressed, and happier, so she could enjoy her family more.

Although she still has periods of depression, she cautions, "It's very easy to put all your problems on the diabetes. It may not be the diabetes at all that's causing your stress. It frequently just adds to other stress."

### What's Normal?

There are endless coping techniques. Some deal directly with the problem, others serve as detractors or energizers to help you approach the problem later. Sometimes a problem diminishes in importance when a fresh perspective is obtained. The diabetes didn't go away, but you feel better about fitting it in your life. Even the most off-the-wall idea could be a good coping technique. For instance, you could:

- Share feelings with a friend or relative.
- Listen to your favorite music.
- Take a photography class for fun.
- Keep a journal (for your eyes only).
- Set up a reward system for improving compliance.
- Speak in pig-Latin for the rest of the day.
- Walk around the block, forward or backwards!
- Make a list of all the things you like to do and when you did them last.
- Re-read your diabetes education materials.
- Record all the times you laugh for a week.
- Take a stress management course.
- Take a cat nap every day.
- Sing a favorite song.
- Buy a joke book or cartoon book and read it!

A diabetes-related crisis could trigger emotional baggage—such as anger—about the intrusion of diabetes, and coping needs may change. If

you feel you're not coping well and are unable to pull yourself out of it, talking with a family member, good friend, or counselor is the best option.

Coping with diabetes is tricky. Just when you think you've got it licked, something may come along that upsets your emotional balance. Often people can identify at least a few things that help them feel better when they're upset or depressed. Some may call a friend they haven't seen in a long time. Others may pre-

fer to write limericks! The important thing is to do something, and if that doesn't help, try doing something else.

Facing the difficulties of diabetes and working toward successful management requires some effort, but the rewards make it worthwhile.

(Note: This article appeared in *Living Well With Diabetes*, Winter, 1990, pp. 7, 9, 10. Reprinted with permission from the International Diabetes Center.)

## Pregnancy raises risk of Type II diabetes

by K.A. Fackelmann

Each successive pregnancy may slightly elevate a woman's risk of developing Type II diabetes later in life, according to a new epidemiologic study. If confirmed, the findings may eventually help unravel the mechanism underlying the development of Type II, or non-insulin dependent, diabetes—a condition less severe than insulin-dependent diabetes, usually affecting people after age 40.

Scientists know that obesity and a family history of diabetes increase a person's risk of getting Type II diabetes. Age also boosts the risk, because the pancreatic beta cells that produce insulin—the hormone that helps the body use sugar—work less efficiently as people get older. Past studies have hinted that pregnancy increases a woman's chance of later developing non-insulin-dependent diabetes, but many scientists pointed to weight gain during pregnancy to explain that association. Now, a report in the Nov. 2 *New England Journal of Medicine* identifies pregnancy as an independent risk factor for Type II diabetes—a risk not explained by obesity.

Donna Kritz-Silverstein, Elizabeth Barrett-Connor and Deborah L. Wingard of the University of California, San Diego, studied 1,186 white, upper-middle-class women age 41 to 92. The scientists took reproductive and medical histories and calculated each volunteer's body mass index, a measure of obesity. When they gave subjects the glucose tolerance test, a standard measure of how well the body processes sugar, they found 326 women had impaired glucose tolerance—flawed glucose metabolism that leads to Type II diabetes in some cases. And 146 other women had Type II diabetes.

After controlling for age, obesity and family history of diabetes, the researchers found each pregnancy boosted a woman's risk of developing Type II diabetes after age 40 by 16 percent. Each pregnancy increased a woman's chance of developing impaired glucose tolerance by 10 percent, they found.

That risk may be important for women with multiple risk factors, comments Maureen I. Harris, an epidemiologist at the National Institute of

Diabetes and Digestive and Kidney Diseases in Bethesda, Md. A family history of diabetes remains the most important risk factor, she says. In the California study, women with a family history of diabetes ran twice the risk of getting Type II diabetes compared with women who had no such history, Kritz-Silverstein says.

While women can't do anything about their inherited susceptibility to Type II diabetes, they can lower their risk by losing weight if they are obese, Harris says. And if further research confirms the link between pregnancy and diabetes, some women might consider keeping their pregnancy rate low. "The number of children people have is a personal decision," Harris says. "But it seems to me it's important to know whether pregnancy does lead to an increased risk for diabetes."

Although some women develop a temporary, mild form of diabetes during pregnancy, the California scientists did not determine the incidence of such "gestational diabetes" among women in the study. Many of the women bore their children before doctors began screening for gestational diabetes, Barrett-Connor says. Scientists know that women who get gestational diabetes run an increased risk of Type II diabetes as they age, she adds.

Barrett-Connor and her colleagues speculate that pregnancy puts a strain on the mother's beta cells, a strain that can lead to Type II diabetes much later, especially if the woman is overweight or has inherited poorly functioning beta cells. During pregnancy, the researchers suggest, pancreatic beta cells must produce more insulin to keep the developing fetus nourished with a constant supply of glucose. At the same time, the mother's body tissue must become resistant to insulin to ensure that the extra glucose load goes to the fetus. Scientists know that Type II diabetes have chronically high blood insulin levels and are insulin resistant, the California researchers note.

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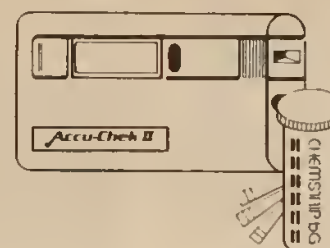
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## Ask Dr. James

by Ronald James, M.D.



Ronald James, M.D., long-term insulin-dependent diabetic, directs Midwest Diabetes Treatment and Education Center, Columbia, Mo. Dr. James is also the Medical Director of the Missouri Diabetic Children's Camp, Inc.

(Note: If you have any questions for Dr. James, please send them to the editor. The only questions Dr. James will be able to answer are the ones used in his column.)

***If sugar is given for a reaction, how long does it take to leave the system under normal circumstances and if the system is overloaded?***

This will depend on the type of sugar that is used. Glucose requires digestion and will be absorbed quite rapidly (within 10 to 20 minutes) and thus will leave the system very rapidly. On the other hand table sugar (sucrose) has to be digested to glucose and fructose. Although this occurs rapidly it does take time. Thus the sugar will remain in the intestinal tract and present in the blood stream longer than if glucose is taken. For the most part, sugars given in reasonable amounts will affect the blood glucose for 30 minutes to one hour. On the other hand, if the system is

overloaded (I assume the person takes more than is necessary to treat the insulin reaction) it may take a couple of hours or so for it to leave the system. This, of course, will vary from one individual to another. If one takes sugar in the form of sweets — for example, cake — its effect may be even longer because the starch in such products requires digestion and will affect the blood glucose for the next several hours.

***My fiance has diabetes and I wonder if I should consider marrying him? I have heard long term diabetics endure many chronic complications.***

The bad news is that long term diabetics frequently develop many chronic complications. The good news is that with appropriate treatment and control of diabetes over the long term most of these chronic complications can either be delayed or prevented. It should be recognized that there is some possibility that anyone with diabetes for a long time will develop some complications. Therefore one's decision with regard to this is a philosophical one and will depend on his/her personal point of view.

***What is Glucagon? Do you recommend that diabetics obtain some? How does it work and what is its purpose?***

Glucagon is a hormone produced by the alpha cells of the pancreas. It is in the form of a peptide, which is a small protein molecule. When given by injection it works to treat an insulin reaction by stimulating the breakdown of starch stored in the liver to glucose. I do recommend that diabetics taking insulin have Glucagon available for their friends, relatives or others around them to use in treating insulin reactions which are so severe they are unable to take sugar in some form by mouth.

## Control diabetes — it is important

by Timothy Long, M.D.  
Family practice physician on the medical staff at  
St. John's Mercy Hospital.

Excessive thirst and urination, fatigue, slow healing cuts, skin lesions which become infected and difficult to heal, irritability, a change in vision—these are classic symptoms of Type I insulin dependent diabetes mellitus.

Weight loss despite intense hunger and overeating can also be a sign. If you experience any of these symptoms, you should call your doctor.

What is Type I diabetes? This is a disease in which the body does not correctly use carbohydrates (sugars and starches), which are its chief source of energy.

During digestion, carbohydrates release a form of sugar, glucose, into the blood. The increased blood levels of glucose stimulate the pancreas to produce the hormone insulin. Insulin helps glucose move from the blood to body tissues for fuel or to the liver for storage until it is needed.

In a diabetic, either the pancreas produces insufficient insulin or the body is unable to respond to insulin. High sugar levels build up in the blood instead of being transported to the tissues to be used as fuel. Some of the excess blood glucose is filtered from the blood by the kidneys and passed out in the urine.

The most common complications of uncontrolled diabetes are heart disease, atherosclerosis, stroke, kidney disease and blindness. The goals of treatment are to maintain normal blood glucose levels and lessen and delay complications.

The cornerstone of successful diabetes management is a balance of insulin injections, diet, weight and exercise, monitored by blood and urine testing.

Insulin injections are timed to improve glucose use throughout the course of a day and to avoid wide swings in blood sugar levels. The type of insulin and timing of injections must be coordinated with the timing

and content of meals.

Exercise also affects insulin requirements. Extra exercise can reduce the need for insulin because exercise "burns up" sugar—less than normal exercise may increase the need.

Diet is crucial. Because diabetes is often associated with high blood fat levels, a low fat diet is essential. Increasing complex carbohydrates (derived from natural sources) is recommended, and refined sugars should be kept to a minimum.

Fiber plays an important role in managing diabetes. For reasons not yet understood, fiber slows or reduces the absorption of sugar in the digestive tract. Calories count, too. A young diabetic needs sufficient calories for normal growth and older diabetics need to maintain appropriate weight.

Maintaining the delicate balance between insulin injections, diet and exercise is essential. Blood and urine tests monitor the balance.

A diabetic can lead a normal life by controlling blood sugar levels, but there is not yet a cure for diabetes.

(Note: This is part of an article that appeared on July 6, 1989, in the *Franklin County Tribune*, Union, Missouri.)



## Studies examine obesity and salt sensitivity in blacks

Two recent reports in the medical literature concern studies on the prevalence of obesity in adult black men and the effects of a high-salt diet in black men. Both obesity and hypertension are associated with diabetes, and both have been linked to the high prevalence of diabetes in the black population.

In a report published in the *Journal of the American Medical Association* (September 15, 1989, Vol. 262, No. 11), "Are Racial Differences in the Prevalence of Diabetes in Adults Explained by Differences in Obesi-

ty?", CDC epidemiologists reported on a study involving more than 14,000 Army veterans from the Vietnam war era. The study included 12,558 white men and 1,677 black men age 30 to 47. The scientists found that in every weight, age, and socioeconomic category blacks had higher rates of diabetes or fasting hyperglycemia. They concluded that "These data provide evidence that the higher prevalence of diabetes found among blacks is not explained by differences in obesity."

Investigators at General Clinical

Research Center in California and Massachusetts are examining possible causes of hypertension in black and white men. In a report published in *Research Resources Reporter* (September 1989, Vol. XIII, No. 9), "Racial Differences Observed in the Response to Salt in Hypertensive Men," they describe studies in black men and white men with normal blood pressure or moderate hypertension and their physiological response to high dietary salt. The findings, say the researchers, may help explain why hypertensive blacks tend

not to respond to certain therapies for high blood pressure and why they have accelerated rates, at all ages, of cardiovascular and kidney damage.

Copies of the *Reporter* are available from the Research Resources Information Center, 1601 Research Boulevard, Rockville, Maryland 20850, telephone (301) 984-2870.

(Note: This article appeared in *Diabetes Dateline*, Volume II, Number I, Spring 1990. Published by the National Diabetes Information Clearinghouse.)



## Pancreas transplant: one man's drama

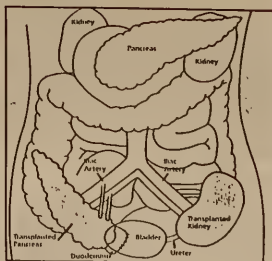
Lewis Ehrlich created quite a stir when he was hurriedly admitted to Beth Israel last June. Drama pervaded the pharmacy where Ehrlich's medications were being prepared and the laboratory where technologists performed last-minute tests. Nurses who had treated Ehrlich during previous hospital stays visited his room in droves, rooting for his success. When the much-anticipated operation got underway, residents and medical and nursing students crowded around the table, making way for the kidney and the pancreas which surgeons gingerly removed from an ice chest and sewed into Ehrlich's opened abdomen.

"I was Rocky going to a big fight," said 40-year-old Ehrlich, who no longer requires the daily kidney dialysis and insulin shots he needed before becoming Beth Israel's first double transplant recipient. Although kidney transplants are performed routinely at Beth Israel, caregivers familiar with the debilitating complications of diabetes from which Ehrlich suffered were eager to see the hospital's first pancreas transplant performed. "I was a celebrity patient," laughs Ehrlich, a husband and father of two.

Complications of diabetes. Before his operation, Ehrlich was one of a half million Americans with type 1 diabetes, a disease in which the body does not produce sufficient insulin. Though regular insulin injections could keep Ehrlich alive, "we could not prevent diabetes' long-term secondary complications," says Dr. Michael Shapiro, who conducted the organ harvest with Dr. Clarence Zimmerman, and then performed Ehrlich's transplant. In varying degrees, Ehrlich suffered from most of the complications to which diabetics are prone including diseases of the kidney, eye (often resulting in blindness), nervous system, and of the vascular system which causes heart problems, strokes, or decreased peripheral circulation (sometimes resulting in amputation).

Working with Zimmerman and Dr. Michael Steer, Shapiro has now performed five transplants of the pancreas—a soft, 4- to 6-inch gland behind the stomach that, among other functions, produces insulin. Beth Israel is one of 90 centers in the United States performing the transplant—an operation "at the interface of basic research and clinical practice," according to Shapiro.

Ehrlich enjoys the notoriety of being a Beth Israel first. "I was the talk of the floor—the double transplant patient." Before the procedure, Ehrlich says, "I was a zombie. I'd push myself into work every day after dialysis." On a prescribed no salt, sugar, or protein diet, Ehrlich needed an average of five daily shots of insulin. A plumber, Ehrlich collapsed on the job one day with a simultaneous stroke



*Transplant surgeons don't remove the recipient's organs but situate the donated ones in new spots. Lewis Ehrlich has the pancreas and kidney with which he was born, and much lower in his abdomen—connected to the bladder and iliac arteries—are the organs he received in the transplant.*

and heart attack. "He was dying," says his wife Alba, who waited nine hours for the surgeons to complete her husband's transplant.

The drama of transplants. For Shapiro, the drama had started 17 hours before when the prospect of the transplant began to unfold. A man died in the hospital, and his grieving family decided to donate his organs. That family's difficult decision, and some rather unremarkable-looking organs became the points around which the hospital staff rallied.

To assure the match, the New England Organ Bank had conducted compatibility tests with the donor's tissue samples, and serum previously collected from Ehrlich.

It took two and a half hours for the surgeons to retrieve the kidney and pancreas which is "not an easy organ to remove because it has many small vessels attached to it," says Zimmerman.

Both organs are pampered and prepped in what is called "backtable work." As if at a basement workbench, the surgeons sit at a sterile, draped table, and flush the donor's blood from the chilled kidney and pancreas, trimming and arranging blood vessels for the organ's eventual fitting into the recipient's body.

Ehrlich now has three kidneys and two pancreases because the transplant surgeons don't remove the recipient's organs but situate the donated ones in new spots where they work equally well (see diagram). The kidney and pancreas are sewn to the bladder and the iliac arteries to receive blood flow. Within a few hours, the recipient's blood-sugar levels are measured to determine whether the pancreas is working properly.

**The threat of organ rejection.** A year after his operation, Ehrlich says, "I'll always be a transplant patient,"

for whom there will always be the threat of organ rejection. Shapiro "still watches me like a baby," laughs Ehrlich. Shapiro assures him, "We'll always watch you, but you shouldn't worry, I'll worry for the both of us."

One problem with the transplant is that "we don't really have a good method of following the pancreas for rejection," Shapiro explains. "When the kidney fails, we know it right away, but with the pancreas, we have to lose 90 percent of the islet function before the blood-sugar level changes." The islets of Langerhans are those cells within the pancreas that manufacture insulin, regulating the glucose or blood sugar levels.

Although there is a 10 percent chance that patients won't survive the transplant surgery, most people prefer the risk to the complications of the disease. Shapiro says a prospective transplant recipient will tell him, "Go ahead and do it. I don't want to be blind and an amputee." Ehrlich remembers being very depressed about the quality of his life before the surgery, so he had no hesitations about the experimental procedure.

The results. Ehrlich has not developed further symptoms of the diabetes-associated problems that racked his body before the transplant, but,

## Simple diabetes test

(Continued from page 4)

Massimo Trucco, M.D., who pioneered the test. If high risk is detected, he adds, the child can be closely monitored to prevent a life-threatening crisis should diabetes develop.

"We may not be able to prevent diabetes, but we will have that person in the system," says James R. Gavin III, M.D., Ph.D., chief of the diabetes section at the University of Oklahoma Health Sciences Center.

Through analysis of a small blood sample, medical laboratories can determine in 24 hours a patient's risk of developing type 1 diabetes, says Dr. Trucco, associate professor of pediatric, human genetics and epidemiology at the University of Pittsburgh School of Medicine.

Scientists believe insulin-dependent diabetes mellitus is an inherited disease in which the body's immune system mistakenly wipes out healthy insulin-producing cells located in the pancreas. Searching for a genetic clue to the misguided attack, Dr. Trucco and his colleagues focused on genes responsible for human leukocyte antigen (HLA), proteins that help the body's immune system zero in on invaders.

Pinpointing one specific position on a gene called HLA-DQ, they found that certain amino acids—building blocks from which proteins are constructed—appear to hold the key. In a spot where most people have gene pairs with either one or two aspartic acids, most type 1 diabetics have two acids that aren't aspartic. Without aspartic acid at the right spot, Dr.

Shapiro cautions, "we haven't proved we can prevent or arrest diabetes' secondary complications."

Preliminary studies at the University of Minnesota on the development of diabetic retinopathy reveal that in three years after the transplants, there is no real difference between people who got a kidney and a pancreas, and those who got the kidney alone. "After the three-year mark however," Shapiro points out, "the pancreas patients stabilized, while in others, eye disease continued to progress." German scientists have found that peripheral vascular disease may be reversed relatively quickly after a pancreas transplant.

While surgeons await greater evidence that the pancreas transplant is worthwhile, Alba Ehrlich says that for the first time since they were married 15 years ago, she feels confident she can look forward to a future with her husband. "We can make plans," she says. They want to go on a cruise—the cost of which is equal to a monthly bill for dialysis. At those costs, Ehrlich, and those who cheered him on, hope he keeps his new kidney and pancreas.

(Note: Reprinted with permission from *Wellbeing Magazine*, Beth Israel Hospital, Boston. ©The Beth Israel Corp., 1989.)

Trucco notes, the insulin-producing beta cells are extremely vulnerable to the "killer" T cells of the immune system.

A study by Dr. Trucco and his colleagues found that a non-aspartic/non-aspartic gene pairing at the critical position signaled a 107-times-greater risk of developing type 1 diabetes. Since this genetic marker is at least 10 times more predictive than any other known HLA marker, the next step was finding a practical way to test for it without using radioactive materials or requiring expertise in molecular biology. The development of a simple test, involving inspection of genetic material from white blood cells, was announced at the American Diabetes Association's scientific sessions in 1989.

The exact sequence of events that leads to beta cell destruction is still a mystery. So is the identity of any other gene that may play a part in diabetes susceptibility. Dr. Trucco notes, "Actually, we are killing ourselves to find it."

Unlike earlier antibody tests, the new procedure predicts risk before the destruction of insulin-producing cells has started. In the future, the new test might be a step in preventing type 1 diabetes, perhaps by thwarting T cells before they attack.

"One of these days it's going to be pretty important to identify someone at risk," says Charles M. Clark Jr., M.D., past president of the ADA. "And we're going to be able to do something about it."

(Note: This article appeared Spring, 1990 in the *News-Press*, Ft. Meyers, FL.)

## Erythropoietin — an update

(Editor's Note: Many diabetics experience renal failure and must choose kidney transplantation or dialysis treatments. Often, the long-term diabetic with kidney disease already has advanced cardiovascular problems before dialysis is needed. Many times diabetics do not handle dialysis treatment well and do much better with a kidney transplant. The NFB Diabetics Division Committee on Renal Problems recommends that diabetics who must choose between transplantation and dialysis, give strong consideration to having a kidney transplant.)

As reported in the last issue of *Common Concerns*, the Food and Drug Administration has approved the use of erythropoietin (EPO) to treat anemia in people with chronic renal failure. The Health Care Financing Administration announced that Medicare will pay for part of the cost of the drug. Here are some commonly asked questions and answers about EPO.

### WHAT IS ANEMIA?

Anemia is a medical term which means the body does not produce enough red blood cells. Red blood cells are the means by which blood carries oxygen to the tissues and carbon dioxide back to the lungs. People who are severely anemic often feel tired, dizzy, cold, have head-

aches, and have trouble tolerating activity or exercise. The body's red blood cell production is regulated, in part, by a hormone called erythropoietin. The kidney is the major site of erythropoietin production in adults.

### WHAT CAUSES ANEMIA?

Many people with kidney failure are severely anemic. The primary reason for this is that people with kidney failure do not produce enough erythropoietin. The process of hemodialysis itself can also contribute to anemia because of red blood cell loss, but usually not to a significant degree.

### HOW IS THE DEGREE OF ANEMIA MEASURED?

The degree to which a person with kidney failure is anemic can be measured by testing a blood sample to determine the person's hematocrit level. The hematocrit level is expressed in a number. The number represents the amount of red blood cells in your blood in relation to your total blood volume. You may wish to consult a member of your medical team to discuss your current and optimal hematocrit levels.

### HOW IS ANEMIA TREATED?

The approved method of treatment for severe anemia has been blood transfusions. Many people with chronic kidney failure have received

blood transfusions on a regular basis for long periods of time. As with most treatments, there are risks involved with blood transfusions. One risk is the build-up of antibody levels which can decrease a person's chance of having a successful kidney transplant. With EPO, some people with chronic renal failure can have their anemia treated successfully without blood transfusions.

### WHAT IS EPO?

The drug industry has created human erythropoietin using genetic engineering. In this process, the human genetic code is used to instruct cultured cells to make large amounts of hormone. This new drug, recombinant human erythropoietin (EPO), has been used experimentally. Studies from these experiments, called clinical trials, show that people are less anemic and have fewer anemic symptoms after being treated with EPO. These clinical trials were done on groups of people on hemodialysis. There are clinical trials being done now on groups of people on peritoneal dialysis.

### WHAT ARE THE SIDE EFFECTS OF EPO?

The most common side effects reported from the clinical trials are increased high blood pressure, seizures related to high blood pressure, clotting, and access problems. If you

take EPO, your medical team will monitor you carefully for these complications, which can be controlled in most cases.

### HOW MUCH DOES EPO COST AND WHO CAN GET EPO?

ESRD facilities are reimbursed a fixed amount (called a composite rate) for each dialysis treatment. Medicare proposes that the cost of EPO given to dialysis patients be paid for by adding \$40 to the ESRD facility's composite rate payment each time EPO is given. If high doses (10,000 units or more) of EPO are given, an additional \$30 can be authorized each time with medical justification. The approximate average cost per year for a person receiving EPO would be \$4,000 - \$6,500. Medicare will pay 80% of the cost of EPO for each Medicare dialysis patient receiving this drug.

Because of possible side effects or other existing medical conditions, not all people on dialysis may be candidates to receive EPO. If you have any questions or need further information about EPO, contact a member of your medical team.

(Note: This article appeared in *Common Concerns*, Volume 2, Number 3, September, 1989. Published by Renal Network Consumer Committee.)

## You asked

by John S. Hoff, Esq.

### QUESTION:

How do I legally designate that I wish to be an organ and/or tissue donor, and what ensures that my gift will be honored?

### ANSWER:

It is relatively easy to designate you want to be a donor, and thoughtful and informed communication is the best way to ensure someone will benefit from your gift.

First, a bit of history: In 1968, as a result of the encouraging prospects for organ and tissue transplantation, the Conference of Commissioners on Uniform State Laws proposed the Uniform Anatomical Gift Act (UAGA), which was eventually passed by Congress and adopted by all 50 states and the District of Columbia. It allows individuals the right to make anatomical gifts for the purposes of transplantation, therapy, medical research, or education.

This Act introduced two popular alternatives for you to indicate your wish to be a donor: signing a donor card or indicating it in the space provided on a driver's license. Donor cards are available from your local organ procurement organization. Both the donor card and the driver's license require two witness' signatures. Their advantage is that they can be conveniently carried in a wal-

let or purse for verification. Their disadvantage is that they may become separated from the holder while he or she receives treatment at a hospital and therefore may not be noticed by hospital personnel.

Two other ways you may formally indicate your desire to donate are in a Living Will or in a Last Will and Testament. The Living Will essentially allows you to specify that, in the event of suffering some severe injury or illness that is terminal, you are refusing any life-sustaining procedures and will be permitted to die naturally. Most states have a space on the Living Will for you to specify what treatment you do or do not want. The option to become an organ and/or tissue donor may be indicated here. (You should know that if you wish to become an organ donor, medical staff will, after you have been declared dead, keep your body on a ventilator to maintain blood flow to the organs for the purpose of transplantation.) You may also indicate the wish to become an organ and/or tissue donor by making a provision in your Last Will and Testament; however, it is not necessary to include a statement about donation in your Will if you have already signed a donor card or indicated your gift on your driver's license.

These four options, though viable

and legal in every way, come with a strong caveat.

In each case, you should bring any written declarations to the attention of your family members. At the time of your death, your legal next-of-kin will be, by law, advised of the opportunity to donate organs and tissues for transplantation, and be asked to give formal consent for this gift. You may know this as the "Routine Inquiry" or "Required Request" Law, which was adopted in 1986 by the federal government. This law also specifies the order of family members who can make the decision: your spouse, an adult son or daughter, either parent, and then an adult brother or sister. Since donor cards and driver's licenses require two witness signatures, it would be to your advantage if these witnesses were members of your family.

When hospital staff are in possession of a document such as the donor card or driver's license, they may use this document to inform a family about their loved one's intention to donate.

Most often, families who learn that a donor card exists will comply with their loved one's wishes.

If you should change your mind about donating, you may destroy your donor card, cover over the statement on your driver's license (be sure to notify the Department of Motor Vehicles the next time you renew your license), or execute a docu-

ment revoking the gift from your Will.

You may be interested to know that in 1997, in response to the public's and medical community's growing concern over the shortage of available organs for transplantation, the National Conference of Commissioners on Uniform State Laws made several revisions to the Uniform Anatomical Gift Act. The new Act would, among other changes, make it unnecessary to have witnesses on the donor card and restate more clearly that a donor may give even if the donor's next-of-kin does not agree to the donation. The Revised Uniform Anatomical Gift Act (RUAGA) has been distributed to individual states and American territories for consideration and adoption. To date federal legislators have not sanctioned any changes to the original Act. Naturally, we can expect much debate before any changes are made.

In conclusion, although there are several ways to declare your wish to donate, the final decision is left to your next-of-kin. So please discuss your decision with your family and with others important to you and your family: friends, clergy, physicians, and lawyers.

For more information, contact the Washington Regional Transplant Consortium.

(Note: The above appeared April, 1990 in *WellSpring*, a pamphlet published by the Washington Regional Transplant Consortium.)



## A celebration of life

by Royanne R. Hollins



Royanne R. Hollins says that life is wonderful and precious and "there is so much to look forward to in the future."

It is wonderful to be alive. What does it mean to "celebrate"? It means to (1) perform with appropriate rites, (2) honor with ceremonies, or (3) extol. It is wonderful to be alive! A celebration of life.

Diabetes ... why me? Oooh, that is the "D" word, isn't it? It is not wonderful having diabetes. Those of us with diabetes have a lot to do. We must test our blood sugars, work closely with our health care team to set appropriate goals for our lives, watch our diets carefully, and take extra care of ourselves that others do not have to be concerned about. Life is not easy for people with diabetes. Balance is a key in our lives. We are constantly walking a tightrope that is tightly strung. If the tightrope sways too far to the left or to the right then we may have problems.

So, what about this life we have to live? Well, personally, I would not trade this life for any other. I may not enjoy diabetes, but I enjoy my life! Life is wonderful. Life is precious.

Diabetic complications ... why me? Oooh, that is the "D.C." term, isn't it? It is terrible to think about. I do not know why I have these complications. I do know, however, that there is a greater plan for my life that I am not personally aware of at the present time. Sure, there are troubles with my complications and *any* complications of diabetes. These troubles and complications are not so wonderful. There is a lot that needs to be done when you experience complications. In my case, there is the necessary education for life skills, mobility training with the white cane and/or guide dog, overcoming embarrassment, Braille lessons and special needs. I *am* special after all!

I would not trade this life with anyone. Life is wonderful. Life is precious. Life is special.

Throughout the years of living with diabetes and coping with complications, I have met some absolutely super, special people. I cannot stress

the words "super" and "special" enough. There are the other people with diabetes that I have met and networked with. I now have more friends with diabetes than acquaintances without diabetes. Some of these friends have experienced life-threatening obstacles with their complications. They have been an inspiration to me more than they will ever know. Some of these friends have not experienced any complications at all. They are some of the lucky ones. My health care team has been tremendous. The endocrinologist is the "team leader". He is as close to a "perfect" doctor as you can get. The ophthalmologist is very caring and optimistic at *all* times. Several of the nurses involved on the team are very special friends of mine. They reach out to my humanity and not just my disease. They are intimately involved in education and support of all kinds. The dietitian on the team is involved in re-education, having to explain the "new and improved" diabetic meal plan.

These special people have touched numerous lives, not just mine, in special ways. They have touched our lives through our individual needs. Each of us have been touched in different ways. Some by the caring of the physician. Some by the optimism of the physician. Some by the support and interaction with the nurses. Some by much needed education from others on our team. This is all a part of our celebration of life.

I would not trade my life with anyone. Oh, sure it is not the greatest thing living with diabetes, but this life is a celebration of life. If I were able to live my life without diabetes, I would do so gladly! Life is wonderful. Life is precious. Life is special. Life is a celebration.

Yes, this is a celebration of life. We don't sit down and quit. There is so much to look forward to in the future. We can help one another, hold one another up. We can lean on one another as necessary without feeling guilty or burdensome. Many of us have children to raise in a moral and upright manner ... what a challenge. Many of us are experiencing diabetic complications of various severity ... eye disease, blindness, kidney malfunction, amputation, heart problems ... more challenges.

Challenges strengthen us. We are living a celebration of life daily. It may not seem like it at the time, but we are all part of a bigger plan that we may not understand right now, and that is okay. We are given this precious gift of life to live in celebration.

In honor of this celebration of life, let's help one another ... volunteer some of our time to talk with others ... share our compassion and knowledge with others. We can help. We do make a difference.

This is a celebration of life!



## Look at the fine print

by Claire Hammer, R.D.

Reading food labels can be time consuming and confusing. But with a little practice you will find the information on them not only helpful but fun to read and compare.

With so many Americans being calorie conscious, the variety of foods bearing the terms "low calorie," "reduced calorie," "light," "lite," "low sugar" or "diet" has become almost overwhelming. You will most likely be attracted to products having these terms on their labels but you need to read a little further for the details.

Quite often the terms "reduced calorie," "light," or "lite" will have the same meaning. The calories certainly have been reduced from the original regular product, but that doesn't mean that the calories are reduced to nothing! For example, 1 T. of a regular mayonnaise will contain about 100 calories. 1 T. of a LIGHT, REDUCED CALORIE mayonnaise will contain 45 calories. Quite a savings but still not low enough to be considered a free food choice. The advantage to you is that you may use 1 T. of the LIGHT, REDUCED CALORIE mayonnaise and count it as 1 fat choice. If you had used the regular mayonnaise (100 calories/teaspoon), you would have to count it as 2 fat choices. (Actually it is a little over 2 choices, but that's close enough.)

You may be thinking that 1 T. is more than you may want to use, on your sandwich for instance. Use about 1 tsp. of the LIGHT, REDUCED CALORIE mayonnaise (about 15 calories) and you would not have to count this if done only once a day.

Some LIGHT, REDUCED CALORIE salad dressings can be as low as 6 calories/teaspoon. This is low enough that you would not have to count 1 tablespoon. But if you use more than 1 tablespoon remember the calories will be more also.

As you can see "light," "lite" or "reduced calorie" foods certainly do have their place in your meal plan. But you do have to read labels carefully.

"Low sugar" products are also something that you might want to check out. Many "low sugar" fruit spreads are both tasty and fairly low in calories. (Manufacturers are not permitted to call these products

"jam" or "jelly" because the sugar content does not meet the standard for a true jam or jelly.) Many low sugar spreads are about half the calories of regular jam or jelly, about 2 tsp. = 16 calories compared with 35 calories of real jam or jelly. If you only used 1 tsp. (8 calories) you would not have to count this small amount.

As soon as you go to the dietetic foods section of your grocery store you will notice a rise in prices. Many of the foods in this section are unnecessary but you may be interested in a few. For instance, you may be able to find a salad dressing that is practically calorie free. Many of them contain only 1 or 2 calories per tablespoon. If you are on a very low calorie meal plan you may want to try some of these items. However just because an item is in the dietetic foods section of the store, don't assume that it is OK for your meal plan without still checking out the fine print. Some foods in that section of your store are not that low in calories and "dietetic" may refer to a product that is low in sodium or cholesterol and may be loaded with sugar and calories.

"Sugar-free" foods are attractive to many people. Again read the label to see if there may be other ingredients in the food that could contribute calories. Sugar-free soft drinks are practically calorie free and certainly acceptable for you to drink. On the other hand a box of sugar-free instant pudding mix would have other ingredients in it to give you a few calories which should be counted into your meal plan.

Many of these foods that only contribute a few calories do not have to be counted. However if you eat a good variety of them each day or maybe a larger serving of one of them in a day, the calories could certainly add up. A good rule of thumb is that you are allowed 60 FREE calories each day in foods of this type. So if you are going to use a significant amount of these types of foods, keep the number 60 in mind.

As with anything, figuring out these labels can be discouraging until you've mastered it. In the meantime do not hesitate to ask your dietitian about any food product you may want to know about.





### Recipe corner

Ann Terry is a registered dietitian. She works at the State Hospital in Fulton, Missouri and at the Veteran's Administration Hospital of Columbia, Missouri. She graciously calculates the diabetic exchanges and food values for our recipes.

Send your great ideas to the editor. He is the official taste tester and needs recipes to test his taster.

#### Salmon Loaf

Submitted by Gail Bryant  
From Columbia, MO

1 (16 oz.) can pink salmon  
1/2 cup skim milk  
1/4 cup lowfat margarine, melted (one half stick)  
1/3 cup salmon liquid  
3 cups bread crumbs  
3 egg yolks, beaten  
2 tbs. chopped green pepper  
2 tbs. finely chopped onion  
1 tbs. lemon juice  
3 egg whites, stiffly beaten

Drain salmon; save liquid. Flake salmon; heat milk, add bread crumbs and margarine. Let stand five minutes. Add salmon liquid and beat until smooth. Add egg yolks, green pepper, onion, one tablespoon lemon juice and salmon. Mix well. Fold in egg whites. Pour into well greased loaf pan or casserole. Bake at 350 degrees, 40 to 50 minutes or until firm in center. Remove from oven. Let stand five minutes. Invert onto serving plate and serve with or without favorite sauce.

Yield: 6 servings; Calories: 330/ serving; Diabetic Exchange: 3 meats (medium fat), 1 bread, 1/2 fat.

#### Bisquit Tortoni

Note: This recipe appeared in the book *The Doctor's Wife's Thinking*

*Thin Cookbook*, by Eleanor Rubin. It sounds just great!

1 cup water, chilled  
1 cup nonfat dry milk  
1/4 cup lemon juice  
1 Tbs. sugar  
Sugar substitute equal to 1/2 cup sugar  
1 Tbs. Sherry  
1/2 Tbs. almond extract  
1/2 tsp. vanilla extract  
2 Tbs. ground almonds

Chill a small bowl and beaters, then beat the chilled water and dry milk until the mixture begins to thicken. Add lemon juice and beat until this mixture is thick. Next add the 1 Tbs. sugar and sugar substitute and continue beating until the mixture is as thick as cream. Fold in the sherry and extracts and spoon into paper cups (4 ounce size). Sprinkle almonds on top and freeze. Makes about 10 portions.

Yield: 10; Calories: 45; Exchanges: 1/2 skim milk

#### Salsa (for canning)

Submitted by Frances Allen  
From Columbia, MO

6 lbs. firm ripe unblemished tomatoes (about 12 large)  
1 lb. yellow onion (about 2 large)  
1 lb. green pepper (2 large)  
1 large red pimento pepper  
1-1/2 cup distilled white vinegar  
1 tbs. plus 1 tsp. salt  
2 tsp. dry mustard  
2 tsp. granulated sugar substitute  
2 tsp. chili powder  
3/4 tsp. ground cumin  
1/2 tsp. ground black pepper  
1/4 tsp. crushed red hot pepper flakes

Peel, chop tomatoes (I chop with knife); allow to drain in a colander. Chop onions & pepper. In a large pot over high heat, combine all ingredients; bring to a boil. Reduce heat to medium and cook, stirring occasionally (45 minutes). Stir frequently. Keep boiling. Fill sterilized jars and seal lids. Allow 1/4 inch of headspace and wipe rims with clean cloth before sealing. Makes 4 pts.

This can be cooked in an oven at 350 degrees.

Yield: 4 pints; Calories: 25 per 1/4 cup; Diabetic Exchanges: 1 vegetable.

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(Continued on page 21)

## New book: *Walking Alone and Marching Together*

*Walking Alone and Marching Together: A History of the Organized Blind Movement in the United States, 1940-1990, by Floyd Matson.*

### A STORY NEVER TOLD

This book tells a story — as true as it is dramatic — that has never been told before. It is a story of the epochal struggle and ultimate triumph of a singular American social movement, that of the organized blind, which evolved over the space of half a century from a small vanguard of visionary men and women into a nationwide community of fifty thousand members — recognized throughout the world as a major force in the field of blindness and civil rights.

Unlike previous histories of blindness and the blind, which have dealt almost entirely with the work of benefactors and agencies for the blind, this magisterial study by a distinguished cultural historian — Floyd Matson — breaks new ground in focusing upon the actions and aspirations of the organized blind themselves. It follows the progress of the movement from its historical origins in the remote past to the pioneering adventure of its founding in 1940, then through the early years of lonely struggle for the right of the blind to organize (indelibly associated with the name of John F. Kennedy). Then we see the turmoil of "civil war," followed by renewed harmony, and explosive growth in both size and stature — as symbolized by the establishment of the multi-faceted National Center for the Blind.



©1990, 1116 pages  
ISBN 0-9624122-1-X  
\$30.00  
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"This book is an important tool for training professionals who work with minority groups or disabled persons. Every educator who has responsibility for designing and implementing programs to bring minority groups or disabled students into the mainstream should know this story, and no teacher of the disabled should enter a classroom without understanding the aspirations of the blind told in this book."

**Homer Page, Ph.D.**  
Professor of Education  
Graduate School of Education,  
University of Colorado at Boulder

Floyd Matson has lectured and written widely in the fields of minority rights, social thought, and political action. He is the author or editor of eleven books and is the co-author with Jacobus tenBroek of *Hope Deferred: Public Welfare and the Blind* (1959). He also collaborated with tenBroek on the award-winning *Prejudice, War and the Constitution* (1954), detailing the constitutional implications of the evacuation of Japanese Americans from the West Coast during World War II. Professor Matson teaches American Studies at the University of Hawaii.

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## ORDER FORM



## NFB Diabetics Division State Representatives

(Continued from page 19)

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## The editor evaluates blood glucose systems with voice output

by Ed Bryant

Ed Bryant, Editor, *Voice of the Diabetic*, evaluates talking glucose monitoring systems.

In communicating regularly with blind diabetics, health and rehabilitation professionals, I am often asked questions about various glucose meters and voice output devices. The Diabetics Division of the National Federation of the Blind exists to serve diabetics, especially blind diabetics. As editor of the *Voice of the Diabetic* I felt that a straightforward evaluation, giving both good and bad points of each system, will serve the cause of our support and information network. I have evaluated all blood glucose monitoring systems with voice output; keep in mind there is no one glucose monitor that is ideal for everyone. What is comfortable for one person may not be for the next.

Most monitoring systems with voice output include a cassette which explains the meter's operation. It is difficult to record all pertinent operating data onto a cassette, so consumers may have questions about their systems that are not answered. Individuals shouldn't feel bad about asking their health care team or a friend for assistance. Once the diabetic is familiar with his/her monitoring system, and has used it for awhile, he or she should have no trouble obtaining

accurate glucose readings. Remember the adage, "Practice makes perfect."

## Glucose systems with voice output

1. **The Diascan SVM Meter:** Home Diagnostics, Inc., 6 Industrial Way West, Eatontown, NJ 07724; phone toll-free: 1-800-342-7226; in NJ call: 201-542-7788.

This monitoring system is easy to use and by far the best I have tested. I use it everyday. Its greatest asset is that there is no need to put a drop of blood on the test strip pad; blood smeared on the pad will produce an accurate clinical reading. All other monitors require a drop of blood on the test strip pad to obtain a reliable reading.

This system has two small box-like units. The first unit is the Digi-Voice voice box. The Digi-Voice, manufactured by Science Products, gives voice output to the Diascan SVM meter, as well as other meters which are discussed later in this article.

The second unit is the Diascan SVM meter which is mounted on a vinyl wallet for protection. When the wallet is open, a short patch cord attaches the voice box and the glucose meter. The meter and Digi-Voice are sold exclusively by Home Diagnostics and its dealers.

An over-the-shoulder tote bag is included with all orders. The complete set weighs about 1 3/4 pounds.

If the voice box breaks down, a diabetic, with a little assistance, can still check glucose levels while waiting for a replacement to arrive.

An easy-to-understand cassette, with clear operating instructions explaining this system, is included with all orders. A free sample cassette is available upon request by telephoning Home Diagnostics at the number shown above.

The suggested retail price for the Diascan SVM Meter with Digi-Voice, which includes a \$125.00 manufacturer's rebate, is \$510.00.

An independent distributor offers

the Diascan SVM Meter with Digi-Voice, which includes a \$125.00 manufacturer's rebate, for \$360.00 plus \$5.00 handling. This is the lowest price on talking glucose monitoring systems in the United States. Continental Pharmacy "will prepare and file Medicare and private insurance claim forms and will wait for insurance payments." This is the only company selling glucose meters with voice output that makes such a great offer. Contact: Continental Pharmacy, Inc., 3355 Richmond Rd., Suite 191, Beachwood, OH 44122; phone toll-free: 1-800-677-4323. Please see the resource column in this issue of the *Voice of the Diabetic* for additional information about this offer.

2. **The Ames Glucometer-M Meter:** Science Products, Box 888, Southeastern, PA 19399; phone toll-free: 1-800-888-7400.

This system has two small box-like units which are attached by a patch cord. The first unit is the Digi-Voice voice box and the second unit is the glucose meter.

This meter can store 338 glucose readings and will announce the average glucose level of all readings recorded during the previous 14 days. The diabetic should be able to keep his/her diabetes under better control through closer monitoring of his/her condition and make appropriate adjustments, when needed.

A cassette explaining the Digi-Voice and Ames Glucometer-M meter is included; however, there is no instructional tape explaining how to obtain a glucose reading. A tote bag is not offered.

Science Products sells the Ames Glucometer-M with Digi-Voice for \$459.50 plus \$9.50 handling. They are the exclusive dealers for the Ames Glucometer-M with Digi-Voice voice box.

As I previously stated, the Digi-Voice is manufactured by Science products, and supplies voice output to three glucose meters: the Diascan SVM Meter (1), the Ames Glucometer-M Meter (2), and the Lifescan One

Touch Meter (5). The Digi-Voice is extremely easy to use. It has a volume knob which can be set for loud or soft. There is a toggle switch to turn the unit on and to have readings repeated. An ear jack porthole for private listening, an AC adapter porthole, and the data porthole, which connects the meter and Digi-Voice, is also located on the box. The Digi-Voice comes with an AC wall adapter and a 9V Nicad rechargeable battery.

3. **The Accu-Check II Freedom System Meter:** Boehringer Mannheim Diagnostics, Inc., 9115 Hague Road, Indianapolis, IN 46250; phone toll-free: 1-800-428-5074.

This monitor has a finger guide to assist the user in getting a drop of blood onto the center of the test strip pad. Once a drop of blood is on the pad the machine says "start the timer." Some blind diabetics liked this feature and some had trouble getting enough blood onto the pad. This is one of only two existing glucose systems that offers a finger guide. The Freedom System finger guide is definitely the best available. Some diabetics like finger guides and some do not. It may be good for those with shaky hands.

Boehringer Mannheim makes different types of reagent strips, so the consumer needs to make certain he or she purchases the correct type.

The weight and size of this system may be a problem for some; it is large and heavy, with dimensions of approximately 12" x 12" x 7" and a weight of about 11 1/2 pounds.

An easy-to-understand cassette explaining how to use the system is included with all orders. The suggested retail price for the Freedom System is between \$650.00 and \$700.00.

4. **The Beta-Scan Meter:** British-American Medical, 26941 Cabot Road, Suite 115, Laguna Hills, CA 92635; phone toll-free: 1-800-866-1187.

The rights for this glucose system

(Continued on page 22)



## Editor evaluates

(Continued from page 21)

were previously owned by Orange Medical Instruments from Costa Mesa, CA. Orange Medical filed for bankruptcy and no longer exists. Unfortunately, owners of Beta-Scan Meters with Voice Output were not notified. However, Beta-Scan owners will be happy to know that Orange Medical's assets were purchased by British-American Medical. Interested persons can still purchase the Beta-Scan meter, and owners can still have their meters repaired and purchase TREND strips, the reagent strips needed with the Beta-Scan meter.

This meter with voice is one small, box-like unit. Also, this is the only glucose system with voice output that does not require the calibrating of test strips; all strips are pre-calibrated. A tote bag is included with all orders. The complete set weighs about two pounds.

A finger guide that is supposed to help the blind diabetic get a drop of blood onto the test strip pad is included with the system. I have examined the finger guide and found that it's not well constructed.

There is no instructional cassette included with this system. Also, this is the only glucose system that doesn't allow private listening, because it has no ear jack connection.

The suggested retail price for the Beta-Scan glucose meter with Voice Output is \$610.00. The following dealer sells the Beta-Scan Meter (complete kit) for \$499.95 plus \$8.00 handling: LS & S Group, P.O. Box 673, Northbrook, IL 60065; phone toll-free: 1-800-468-4789.

**5. The Lifescan One Touch Member:** Continental Pharmacy, Inc., 3355 Richmond Rd., Suite 191, Beachwood, OH 44122; phone toll-free: 1-800-677-4323.

This system has two small box-like units (the Lifescan One Touch Meter, and Digi-Voice). The Digi-Voice attaches to the meter by a short patch cord. The unit is easy to operate, and the speech is easy to understand. It comes with a 9V Nicad rechargeable battery.

I found the One Touch system fairly easy to use. However, sometimes I had trouble getting a large enough drop of blood onto the correct spot of the test strip pad. Also, if you bleed very much, blood may cover part of your meter. Blood can, of course, be cleaned up, but may be a bit messy.

The cassette explaining how to use the system is included with all orders, and provides good directions for using the One Touch Meter and Digi-Voice.

If the Digi-Voice ever breaks down, the diabetic, with a little assistance, can still check his/her glucose levels while waiting for a replacement to arrive.

As stated earlier, Continental Pharmacy "will prepare and file Medicare

and private insurance claim forms and will wait for insurance payments."

Continental Pharmacy sells the Lifescan One Touch Meter and Digi-Voice for \$439.00 plus \$5.00 handling. This is the lowest price, in the United States, for the One Touch Meter with voice box.

**6. The Lifescan One Touch Meter:** American Foundation for the Blind (AFB), 15 W. 16th., New York, NY 10011; phone toll-free: 1-800-532-5463.

The AFB sells a box called the Touch and Talk, which gives voice output to the One Touch meter. This system has two small, box-like units. The Touch and Talk attaches to the meter by a short patch cord.

As stated in the previous evaluation (5), I found The One Touch meter fairly easy to use, but sometimes I had trouble getting a large enough drop of blood onto the correct spot of the test strip pad.

(Editor's note: I started to write an editorial about the following information, however, decided to have it printed with this article. Consumers should have all the facts before spending hard-earned money on high priced commodities). While considering previously evaluated glucose systems with voice output, I telephoned the different companies and asked pertinent questions about their systems. They were all congenial and more than happy to provide me with information about their products. Any consumer should expect good service when dealing with vendors—especially when the merchandise in which they are interested costs several hundred dollars.

On May 22, 1990, I telephoned the AFB hotline number to get details about the Touch and Talk voice system and how it worked with the One Touch meter. I asked the person who answered my call about the size of the Touch and Talk, test strip calibration procedures, whether batteries were rechargeable, how the operating instructions were explained to blind persons, the cost, etc. That person said she had no idea of the instrument's size, calibration and battery information. She then said that "it" must give this information, as the literature she was reading said "it" did everything. Since she couldn't answer my questions, I asked to speak with someone who could provide answers. She said I could call Customer Service (not toll-free), as they would definitely have the answers.

On May 23, 1990, I again telephoned the toll-free number, and another person said, almost verbatim, the same thing. She said she knew nothing about the merchandise except what she had to read. I then telephoned the AFB Customer Service number for assistance; however, none was forthcoming. The person I talked to there, like the others, couldn't answer my questions. After checking with someone several times, she finally said that she

thought the meter was a little larger than a walkman. She said that the meter speaks "everything." I asked here what she meant by "everything", and she didn't know. She said she was only reading the material provided her. A second person spoke to me, but could not answer my questions. She told me that Lifescan made the entire unit. I replied that Lifescan made the One Touch meter, but they didn't manufacture the Touch and Talk. Realizing she didn't know, she put me on hold, returned and said I would have to call the AFB technical department (not toll-free), and they could answer my questions.

I fail to understand why the AFB Hotline Personnel were not trained to provide me with the Technical Service number. I was told that Customer Service could answer my questions; unfortunately, they could not. Additionally, at least one person in Customer Service apparently didn't know that I should telephone the Technical Service number.

On July 13, 1990, I again telephoned the hotline number. The person I spoke with said, like the others, she knew nothing about using one of these machines and that she just read what was in front of her. She then asked me why I wanted to know details about this instrument because they had sold several, and she didn't think that other customers had asked questions. What an astonishing thing to tell a potential customer! Among the privileges of living in a consumer oriented society is being able to make reasonable inquiries and to receive reasonable answers.

All other vendors selling glucose systems with voice output had well-trained personnel to receive incoming calls. The majority of the AFB staff I conversed with were not trained and even admitted that they knew nothing about the Touch and Talk except what was given to them to read.

On July 16, 1990, I telephoned the Technical Service number. The person there said that the Touch and Talk used one 9V alkaline battery (not rechargeable), and is connected to the One Touch meter by a short patch cord. I was told this system has two small box-like units; no tote bag is offered.

Cassette instructions for the Touch and Talk and One Touch Meter were not offered, but large print instructions were. I requested a copy of the instructions and received them a few days later. These gave absolutely no information on how to use the system; the copy I received was nothing more than a press release for the Touch and Talk. It would be unlikely that any consumer, without previous experience, could operate the system by using the large print copy from the AFB.

On Tuesday, July 23, I again phoned the AFB Technical Service number to see if what I had received were supposed to be instructions or if there had been an error. The person I conversed with said that she

thought there were large print instructions and she would mail them to me.

A few days later, I received the large print instructions. Unfortunately, they explained the Touch and Talk controls, but did not explain how to use the One Touch Meter with the voice box. It would be difficult for any person, without previous experience, to use this system. On July 30, 1990, I telephoned the AFB Technical Service Dept., and asked how I, as a blind person, could obtain a glucose reading using their instructions. A man said that the instructions weren't intended to show blind, or visually impaired people how to test blood glucose readings. He said that the Lifescan instruction manual is included with orders (all companies selling meters include instruction manuals), but that he wouldn't dare tell someone how to use the unit. I replied that if instructions were given as to when to prick my finger, also when, where, and in what position to insert the reagent strip into the meter, and other pertinent details, I, like many other blind diabetics, would have no trouble using the system. I also said that using any glucose monitoring system without previous experience would take practice. He replied that they (the AFB) would never explain how to use the system, as they strongly recommended that all Touch and Talk users seek training from their health care professional. My response was that, if needed, there is nothing wrong with going to your health care team, but it usually costs about \$30.00, and many people do not need assistance from a health professional in order to obtain good glucose readings.

After conversing with the AFB technical person, I telephoned my local diabetes treatment center, which treats approximately 3,000 diabetics. The person I talked to said that, if the patient was a newly diagnosed diabetic, he would recommend that they visit their health care team to learn how to use a glucose monitoring system. He said that this was primarily to make certain that persons with diabetes were keeping in touch with their physician so that the diabetes could be monitored. I was then told that as long as they were under a physician's care, and felt comfortable with using their system, there was no reason that they should make an appointment with their health care team. Some physicians suggest that each patient visit their office to learn the use of whatever glucose systems they have; other physicians do not. Most diabetics who have lost significant vision due to diabetic retinopathy have had the disease at least 15 years. As previously stated, individuals should not feel embarrassed about asking their health care team or a friend for assistance.

Both the AFB and Science Products (2) produce voice boxes that give audio output for the One Touch Meter. Science Products offers a cassette (the AFB does not) with easy-



to-understand instructions on using the system. The AFB offers only large print instructions which explain the controls of the Touch Talk.

The Digi-Voice voice box, manufactured by Science Products, uses a Nicad battery which is rechargeable, and can be used repeatedly. The Touch and Talk, sold by the AFB, uses a non-rechargeable battery, which must be replaced (the battery is not included with orders).

Continental Pharmacy, Inc. (5) is a dealer (vendor) which sells the Lifescan One Touch Meter with Digi-Voice for \$439.00 plus \$5.00 handling. They also offer other incentives. AFB sells the One Touch Meter with Touch and Talk for \$459.00 plus \$8.50 shipping and handling.

In summary: Blind diabetics have the desire and ability to test their own blood glucose levels, thus keeping

their diabetes under better control. As I stated earlier in this column, I feel that the Diascan SVM Glucose Monitoring System with Voice Output is the best on today's market; however, what is comfortable for one person may not be for the next.

I have reported on all talking glucose systems sold in the United States. The strengths and weaknesses of different systems have been provided, plus reports on the

service I received as a potential customer from the different companies. This is important because, as consumers, we deserve and should expect to be treated in a professional manner.

The Diabetesics Division of the National Federation of the Blind is here to serve diabetics, especially blind diabetics. Please feel free to come to us with questions or comments.

## What you always wanted to know but didn't know where to ask

(Resource list)



(Inclusion of materials in this publication is for information only and does not imply endorsement by the Diabetesics Division of the NFB.)

### Equipment

Glucose systems with voice: A comprehensive evaluation has been made on all talking glucose systems sold in the United States. Please see the article, in this issue of the *Voice of the Diabetic*, entitled: "An evaluation of blood glucose monitors with voice output" by Ed Bryant.

Accu-Drop Blood Sample Device: Blind diabetics and/or those with shaky hands may like this device. This instrument has a finger guide which may help diabetics, after puncturing a finger, in getting a drop of blood onto the center of the test strip pad.

The Accu-Drop was designed for bG chemstrips; however, Diascan strips may also be used. We don't know if other reagent strips will work with this device.

The suggested retail price is \$12.00 to \$15.00. Contact: Boehringer Mannheim Diagnostics, Inc., 9115 Hague Road, Indianapolis, IN 46250; phone toll free: 1-800-585-8072.

**Alcom Accent Text-To-Speech Synthesizer:** Converts text on your computer screen to speech, with vocabulary of over 20,000 words. Five models: full-length (\$745) or half-length (\$395) plug-in cards for IBM-PC compatibles; cards for Toshiba laptop models T1200, T1600 (\$625) or T1000SE; stand alone unit with RS-232C link to any computer (\$940); MC cards for microchannel PS-2 (\$895). Supported by all major screen reader programs. Contact Alcom Corporation, 2375 Zanker Road, Suite 205, San Jose, CA 95131; telephone: (408) 922-0855.

**Novolin Pen:** This device looks like a fountain pen and can be carried in either shirt pocket or purse. When drawing insulin, an audible click will be heard for each two units drawn.

A multidose PenFill cartridge slips into the pen for several days' dosage

of insulin. Three different cartridges of human insulin are available: the Novolin R PenFill contains regular human insulin injections (semi-synthetic); the Novolin N PenFill contains NPH human insulin isophane suspension injections (semi-synthetic); and the Novolin 70/30 PenFill contains a mixture of 70% NPH human insulin isophane suspension and 30% regular human insulin injections (semi-synthetic). All PenFill cartridges are sold in lots of five. The suggested retail price is \$13. The suggested retail price for the Novolin Pen is \$39.95. For information contact: Novo-Nordisk Pharmaceuticals; telephone toll-free: 1-800-727-6500.

**Xerox/Kurzweil Personal Reader:** This instrument reads single sheets or bound documents by turning the printed word into DECtalk synthetic speech. Includes a portable optical scanner that interfaces with other computer hardware, plus it is "compatible with...Braille conversion software packages." Contact: Xerox/Kurzweil Personal Reader Department, 185 Albany Street, Cambridge, MA 02139; telephone toll-free: 1-800-343-0311, or in Massachusetts: (617) 864-4186.

### Continental Pharmacy

Continental Pharmacy has over 27,000 products, including a wide range of pharmaceutical items. Large print or Braille labels are available at no charge. Advanced payments aren't required; this pharmacy "will prepare and file Medicare and private insurance claim forms and will wait for insurance payment." No charge for home deliveries.

**SPECIAL OFFER FOR VOICE OF THE DIABETIC READERS:** Continental Pharmacy offers the following specials on glucose monitoring systems with and without voice output.

**Diascan S Glucose Monitor:** Has large LCD readout; limit one meter per person; minimum of 2 vials of Diascan strips must be purchased. Normal retail cost is \$154.00. Your cost is \$0.00.

**Diascan SVM Glucose Monitor**

**with Voice Output:** Blood may be smeared onto the test strip pad and accurate glucose readings can still be obtained. Limit one meter per person; minimum of 2 vials of Diascan strips must be purchased. An instructional cassette and over-the-shoulder tote bag is included with all orders. Normal retail cost with manufacturer's rebate is \$510. Continental Pharmacy sells this glucose meter with voice output (includes a \$125 manufacturer's rebate) for \$360 plus \$5.00 handling. These prices are, by far, the lowest in the United States.

Our editor, Ed Bryant, uses the Diascan SVM system daily, and says that "It is extremely easy to use, and the speech is easy to understand." The manufacturer advertises these Diascan systems as the "most accurate on the market."

**Lifescan One Touch Glucose Monitor with Voice Output:** Limit one meter per person; minimum of 2 vials of test strips must be purchased. An instructional cassette is included with all orders. Cost: \$439.00 plus \$5.00 handling. Like the Diascan S and SVM with voice, the cost of the Lifescan One Touch System with Voice is the lowest in the United States.

To order the above glucose systems, contact: Continental Pharmacy, Inc., 3355 Richmond Rd., Beachwood, OH 44122; telephone toll-free: 1-800-677-4323.

### New Resource List

The Diabetesics Division of the NFB has an updated resource list of aids and appliances for blind diabetics and those losing vision. This list is comprehensive and is arranged under five general headings: General and Miscellaneous, Automatic Insulin Injection Systems, Blood Glucose Monitoring Systems, Large Distributors of Diabetes Equipment/Supplies, and Insulin Pumps.

Sometimes blind diabetics and their sighted friends do not realize that they can continue being independent by accurately drawing up insulin and testing blood glucose levels. Limitations are usually self-imposed and often all that is needed to overcome negative thinking is simply knowing where to go for information.

The new resource list costs \$1.00 per copy and is available in Braille, print, and cassette. Make donations payable to National Federation of the Blind and order from: Annie Weems,

Aids and Appliances Chairwoman, P.O. Box 47765, Oak Park, MI 48237-5465; phone: (313) 592-1567.

### Literature

**Diabetes and the Two of You: A Guide to Managing Gestational Diabetes.** This is a "21-page booklet outlining self-care for women with gestational diabetes. The content is presented in an easy-to-read style, and line drawings illustrate concepts presented.

The booklet was produced by staff at the Patient Education Center at the Medical College of Virginia Hospitals." This booklet was listed in Volume 11, Number 1, Spring 1990, *Diabetes Dateline*. Cost: \$1.75 plus postage and handling. Order from: Patient Education Center, MCV Station, Box 7, Richmond, VA 23298-0001; telephone: (804) 786-2139.

**The Eclectic Renal Gourmet:** by Council on Renal Nutrition of New England. (Spiral bound, 8½ x 11", 129 pages). This book was listed in the March, 1989 issue of *Common Concerns*, which provides information for kidney patients and their families. Cost: \$10.00. Order from NKF of Massachusetts, 344 Harvard St., Brookline, MA 02146.

The following two books are published by Diabetes Center, Inc. (DCI).

**Diabetes: A Guide to Living Well:** by Gary Arsham, M.D., and Ernest Lowe. A DCI press release says, in part, "The reader can choose between three regimens of care: intensive, moderate, loose. The goal is to match the motivation and abilities of each person with a specific level of diabetes care and then to modify or improve the program as necessary. Includes a special chapter for women written by Cathy Feste, author of *The Physician Within*." Cost: \$10.95. Order from: Diabetes Center, Inc., P.O. Box #739-811, Wayzata, MN 55391; phone: 1-800-848-2793.

**Diabetes: Actively Staying Healthy:** by Marion Franz, M.S., R.D., C.D.E., and Jane Norstrom, M.A. This book explains how to develop an exercise program which is good for everyone, but especially diabetics. Cost \$6.95. Order from: Diabetes Center, Inc., P.O. Box #739-811, Wayzata, MN 55391; phone: 1-800-848-2793.



## Food for thought

### New column

(The following is part of a letter to your *Voice* editor, received from Dr. Doug Denning on July 3, 1990: "I am an ophthalmologist in the Independence, Missouri area. I have an interest in diabetic retinopathy since I am a diabetic myself with a fellowship in vitreoretinal surgery including work with diabetic retinopathy." The doctor went on to say that he would be happy to answer questions for patients about diabetic retinopathy and their eyes.

Dr. Denning has made a gracious offer, which is appreciated. If you have questions regarding any aspect of diabetic retinopathy please send them to: Ed Bryant, Editor, *Voice of the Diabetic*, 811 Cherry St., Suite 306, Columbia, MO 65201; phone: (314) 875-8911.

The names of people submitting questions will not be printed with them when they appear in the *Voice*.

### Tape Players

When people become blind they usually need to use alternative techniques to keep up with printed literature. These people can receive a free cassette tape player, from the Library of Congress, which runs at standard (1 7/8 ips) or half speed (15/16 ips).

Library of Congress tapes, as well as the cassette version of the *Voice of the Diabetic*, run at half speed, so a special player like this is needed.

Tape players may be ordered from your regional Library for the Blind and Physically Handicapped; or phone the Library of Congress, toll-free, at 1-800-424-8567. These tape players are mailed as Free Matter for the Blind.

### Important

To: Members of the NFB Diabetics

### Division

From: Ed Bryant, Vice President, NFB Diabetics Division, 811 Cherry St., Suite 306, Columbia, MO 65201; phone: (314) 875-8911.

The *Voice of the Diabetic* is extremely popular. Almost daily, diabetics and interested persons join our dynamic division. Membership in the NFB Diabetics Division costs five dollars per year and includes a free subscription to the *Voice of the Diabetic*. However, production cost per annual subscription of the *Voice* is about \$15.00; obviously we must generate funds to help defray costs.

We rely primarily on donations, advertisers, and the five-dollar annual membership dues. Many of our members pay their yearly dues faithfully; however, there are several who do not. I understand that they may have inadvertently forgotten to renew

their memberships, may be short of funds, or for some reason they think our magazine is free and they don't have to pay. A few individuals have told me that they thought upon joining the division and paying the initial membership fee that they would remain on the *Voice of the Diabetic* mailing list forever at no cost.

To reiterate, our magazine costs money to publish, and we count on members paying their five-dollar yearly dues. We also send membership renewal-fee reminders when they are due.

If anyone can't afford to pay, please let me know and he/she will not be charged. If you are delinquent in paying your annual dues, then get on the ball and get it done. Once your membership dues are paid you are in good standing for another year. If preferred you can pay for up to five years in advance.

Our entire NFB Diabetics Division thanks you in advance for your attention to the above information.

Best regards,  
Ed Bryant

In Memory of  
by Ed Bryant

On Tuesday, July 17, 1990 Annie Parker died from complications of a liver disorder. Annie was the wife of Bill Parker, our NFB Diabetics Division Treasurer.

Bill asked me to print something about Annie's death so that *Voice* readers could make donations, in her memory, to our NFB Diabetics Division.

Annie did not die from diabetes, but she strongly supported our division. She was always ready to reach out and do whatever was needed to help others.

Annie was a Christian lady and the following is, I think, appropriate: "Death is not extinguishing the light. It is only putting out the lamp because dawn has come."

Annie Parker will always be with us in spirit...she won't be forgotten. Please make contributions, in memory of Annie, payable to National Federation of the Blind, and send them to: Bill Parker, 857 Ingleside Rd., Norfolk, VA 23502.

### Spread the Word

If you know someone who may be interested in reviewing the *Voice of the Diabetic*, ask and we will send him or her a complimentary print and/or cassette copy (tapes recorded at 15/16 inches per second). Contact *Voice of the Diabetic*, 811 Cherry Street, Suite 306, Columbia, MO 65201; telephone: (314) 875-8911.

Q. Why can't someone's hand be 12 inches long?

A. Because then it would be a foot.

Knock, knock. Who's there? Orange. Orange who? Orange you glad this is another stupid knock, knock joke!!

## ADVERTISERS

Effective advertising doesn't scream at its audience. It persuades. It sells. The key to cost-effective advertising is making your voice heard where an audience is already listening. *Voice of the Diabetic* offers such an outlet. Make your voice heard. For advertising information contact:

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Ed Bryant, Editor  
811 Cherry Street, Suite 306  
Columbia, MO 65201  
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*Voice of the Diabetic* is a quarterly magazine for anyone interested in diabetes, especially diabetics who are blind or losing vision. The \$5.00 annual membership fee of the Diabetics Division of the National Federation of the Blind (NFB) entitles you to a free subscription to *Voice of the Diabetic*. However, production cost per annual subscription of the *Voice* is about \$15.00, and for this reason we must charge all non-members, health professionals and institutions \$15.00 for an annual subscription. Of course, all donations are accepted and very much appreciated.

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